

Psychosocial experiences of patients with inflammatory bowel diseases

Literature review

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Abstract <p>Inflammatory bowel diseases (IBD) are a rapidly growing health problem in developed countries, especially in Northern countries. Knowledge of IBD is required as health care professionals work with IBD patients in many sectors. IBD is a chronic disease and affects the patient's life in multiple ways, also psychosocially.</p> <p>The aim of the study was to gain an understanding of what kind of psychosocial experiences patients can have when living with inflammatory bowel diseases. The purpose was to collect recent information for nurses and to raise knowledge about psychosocial experiences patients can have when living with inflammatory bowel diseases.</p> <p>Two databases (CINAHL, PubMed) were browsed to collect relevant articles meeting the inclusion criteria. Content analysis was conducted to analyze the data from 11 articles. The following three main categories were created: Psychological experiences; social relationships and work; and experiences regarding health-care professionals.</p> <p>As a conclusion it was found that there is a need to raise awareness about experiences of IBD patients amongst nurses. It was discovered that the psychosocial consequences of IBD are extensive and it is recommended that nurses regard IBD as a wide-ranging disease. Psychosocial experiences not only affect the patient's quality of life but also affect disease activity. Nurses should assess the coping strategies of patients and guide them towards coping with the disease. Careful screening of social problems, fatigue and stress levels should be continuously implemented to prevent unnecessary suffering of the patient.</p>		
Keywords/tags (subjects) Nursing, IBD, inflammatory bowel disease, psychosocial, Crohn's disease, ulcerative colitis, patient experience		
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Tiivistelmä <p>Tulehdukselliset suolistosairaudet ovat yleistynyt ongelma kehittyneissä maissa, etenkin pohjoisissa maissa. Terveystieteen ammattilaiset tarvitsevat tietoa tulehduksellisista suolistosairauksista työskennellessään potilaiden parissa monella eri sektorilla. Tulehdukselliset suolistosairaudet ovat kroonisia sairauksia ja vaikuttavat potilaan elämään monella tapaa, myös psykososiaalisesti.</p> <p>Tutkimuksen tarkoitus oli ymmärtää millaisia psykososiaalisia kokemuksia potilailla voi olla eläessään tulehduksellisen suolistosairauden kanssa. Tarkoituksena oli koota viimeaikaista tietoa sairaanhoitajille ja lisätä tietämystä psykososiaalisista kokemuksista tällä potilasryhmällä.</p> <p>Kahta tietokantaa (CINAHL, PubMed) käytettiin etsittäessä hyväksymiskriteerit täyttäviä artikkeleita. Sisällönanalyysiä käytettiin 11 löydetyn artikkelin analysoinnissa. Seuraavat kolme pääkategoriaa luotiin: Psykososiaaliset kokemukset, sosiaaliset suhteet ja työ sekä terveydenhoidon ammattilaisia koskevat kokemukset.</p> <p>Lopputuloksena todettiin, että tulehduksellista suolistosairautta sairastavien kokemuksia on tuotava enemmän hoitajien tietoon. Tulehduksellisten suolistosairauksien psykososiaaliset seuraukset ovat laajoja ja hoitajien tulisi suhtautua sairauteen kokonaisvaltaisena sairautena. Psykososiaaliset kokemukset eivät vaikuta vain elämänlaatuun, vaan myös sairauden kulkuun. Hoitajien tulisi arvioida potilaan selviytymiskeinoja ja opastaa heitä hyväksymään sairautensa. Sosiaalisen eristäytyneisyyden, uupumuksen ja stressitasojen huolellinen havainnointi on tärkeää, jotta potilaan tarpeettomia kärsimyksiä voidaan ennalta ehkäistä.</p>		
Avainsanat(asiasanat) Hoitotyö, tulehdukselliset suolistosairaudet, psykososiaalinen, Crohnin tauti, ulceratiivinen koliitti, haavainen paksusuolentulehdus, potilaan kokemus		

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1 Introduction

Inflammatory bowel diseases (IBD) are one of the growing Finnish public health problems and becoming very common in western countries (Färkkilä 2014).

According to Niemelä (2002, 3133) there were 20,000 IBD patients in Finland in 2002. Two thirds of them suffer from ulcerative colitis (UC) and one third have Crohn's disease (CD). The number of IBD patients has tripled during the years 1993-2008 and in 2015 the number was over 40 000 - 45 000 (Nykopp 2015; Färkkilä 2014).

According to Molander (2014, 18) the highest number of IBD patients can be found in developed countries. In Europe, the prevalence is higher in northern and western countries, compared to southern and eastern countries.

Knowledge of IBD is needed as health care professionals/nurses work with IBD patients in many sectors. Treatment and follow up is provided in health centers and in hospital gastroenterology, medical, pediatric and other clinics. Primary health care treats long-term follow-up patients, who are in an asymptomatic phase of the illness called remission. (Nykopp 2015.) Various associations and foundations also work with IBD patients. It is possible that because of the present wide-ranging nurse education, there is more need for nurses to specialize in IBD treatment.

People who suffer from any chronic disease are possibly facing several psychosocial challenges due to illness which require understanding especially from health care professionals. The aim of this study is to utilize existing data to gain an understanding of what kind of psychosocial experiences patients can have when living with inflammatory bowel diseases. The purpose is to conduct a literature review, collect recent information for nurses and to raise knowledge about psychosocial experiences patients can have when living with inflammatory bowel diseases.

2 Inflammatory Bowel Diseases (IBD)

2.1 General description and treatment

Inflammatory Bowel Disease (IBD) is a concept including a group of diseases where an essential part of the intestines and/or other parts of the digestive system are inflammatory. IBD's major categories are Crohn's disease (CD) and ulcerative colitis (UC) which are the subject of this thesis. Other IBDs include, for example, collagenous colitis and lymphocytic colitis. (Sipponen & Färkkilä 2013, 472.) Crohn's disease and ulcerative colitis are chronic conditions. The diseases are not contagious, yet heredity creates a predisposition for them. Curative treatment has not been discovered. However, symptomless periods (remissions) fluctuate with active periods (relapses). (Sipponen & Färkkilä 2013; 474, 478-479.) Both diseases mainly occur in young adults aged 15-35 who face the challenge of a changed life. In addition to intestinal symptoms for instance joint, eye and skin problems may occur as a co-morbidity. (Sipponen & Färkkilä 2013, 510; Gillian 2005.)

Potentially located in the whole digestive system, Crohn's disease is mostly active in the small intestines and impacts to the whole bowel wall. Inflammation and healthy areas in the bowel alternate. Diarrhea, constipation and hard stomach pain are the most common symptoms, beside lack of appetite and weight loss. (Sipponen & Färkkilä 2013, 478-480.) Ulcerative colitis is characterized by ulcers and inflammation of the large intestine's and rectum's mucous membrane. The affected area does not include healthy areas, as in Crohn's disease, and it is located as a continuous area from the rectum, potentially covering the whole large intestine. Diarrhea, mixed with blood, and nonspecific stomach pains are typical symptoms in ulcerative colitis. Weight loss can indicate severe inflammation. (Sipponen & Färkkilä 2013, 478.)

Treatment for UC and CD are mainly the same excluding some exceptions. The first aim is to achieve the active IBD to the asymptomatic (remission) phase. (Haavisto 2013, 17.) The following aims are to maintain remission, avoid hospitalization and surgery, minimize the cancer risk, optimize life quality and enable mucosal healing (Molander 2014, 41). Treatments can be divided into medical and surgical therapies.

Corticosteroids are among traditional medicines (Molander 2014, 41-52), while biological medicines are an example of new medicines (Möttönen & Färkkilä 2016, 335). In UC surgery is used only when medical treatment options have failed. Approximately 25-30 % of the patients need a surgery. Typically, the entire colon is removed and ileostomy or ileoanal pouch is formed. Even 70-80 % of CD patients need a surgery in some phase of their life and the surgery comprises for instance considered removal of the inflamed part of the intestine. (Molander 2014, 52; Gillian 2009, 18.) Sometimes temporary colostomy is used to enable rest for other parts of intestine or stricturoplasty is applied to make the narrowed area larger (Veronesi 2003, 42).

The course of the disease cannot be affected by diet or other self-care.

However, balanced nutrition prevents weight loss and helps to maintain general health (Mustajoki 2016). Particularly in CD, the effects of smoking have been researched. The results indicate that quitting smoking has a significant positive effect (Molander 2014, 41; Sipponen 2013, 495). Several alternative treatment options, for instance probiotics, helminth therapy (worms) or leukocyte apheresis have been studied, although not yet recommended due to unfinished studies. (Sipponen 2013, 495.) A person with IBD often needs psychological and emotional support besides medical treatment (Gillian 2005).

2.2 Psychosocial aspects

Earlier IBD was considered only as a psychological illness since there was not any other explanation for it. Sick persons were labelled psychologically immature and incomplete as it was thought that they only did not want to control their bowel movements. Although this belief has mainly disappeared, still some nursing staff and even IBD patients themselves can have some incorrect beliefs concerning the disease. (Gillian 2005.)

Research on the influence of psychological factors on IBD is slightly controversial. For example, studies conducted at the same time in 1990s found opposite results on the influence of psychological factors on IBD exacerbation. (Schoultz 2012, 371.) Nowa-

days some of the studies emphasize and some dismiss the importance of psychological factors (Schoultz 2012, 372). Defining the psychological factors reliably is difficult because of the variation in different researchers' definitions. UC and CD are researched separately and in mixed groups. The patients can be in different stages: remission, long term IBD or recent diagnosis. (Schoultz 2012, 372.) It seems that literature and studies concerning IBD and psychological factors are fragmented and contradictory (Barello, Leone, Danese & Vegni, 2013, 559).

Previous life experiences, resources and weaknesses come together when a person becomes ill with IBD. The person experiences a large variety of changes in emotional life during the diagnosis and after it. Receiving an IBD diagnosis can be a shock or a relief. The person may have been afraid of cancer because of similar symptoms, so it may be a relief to receive an IBD diagnosis instead. A chronic illness brings changes in everyday life. There are issues which are hard to discuss, unless the other person has a similar illness. IBD is often experienced as an embarrassing and shameful disease and seen as a topic to be avoided. Sharing experiences and feelings is important and required. (Gillian 2008, 119-120; Gillian 2005.)

The patient's partner usually closely follows the struggle with the disease. However, conversation with the spouse can be a burden mutually. It may be easier to talk to a less familiar person or a person with the same condition. This person can approach the situation as a listener and the patient can calmly take a stand as a storyteller. Therefore, the best persons to talk to can be semi-familiar people, who do not take the topics in conversation as a personal burden. Peer support is extremely important. Conversation with a doctor may not bring a desired result due to hurry and focusing on somatic symptoms rather than psychological problems. (Gillian 2008, 119-120; Gillian 2005.)

3 Other chronic diseases and psychosocial experiences

The term “psychosocial” refers to the psychological and social aspects of a person (Duodecim terveyskirjasto 2016). Utilized with chronic diseases, the psychological aspects include mental health problems, such as depression, anxiety and low self-esteem. Social aspects can be defined as challenges to maintain social relationships and quality of life or as negative feelings, for example embarrassment and fears.

The definition of chronic diseases is a long duration disease, which generally progresses slowly. Chronic diseases include for instance diabetes, asthma, chronic obstructive pulmonary disease (COPD) and arthritis. (Desroches, Lapointe, Ratté, Gravel, Légaré & Turcotte 2013, 2-3.) Chronically ill patients may struggle to balance between managing their health and demands of their life (Yen, Gillespie, Rn, Kljakovic, Brien, Jan, Lehnbohm, Pearce-Brown & Usherwood 2010, 13). Chronically ill patients’ psychological needs are sometimes recognized poorly. Therefore, these patients’ treatment models should be developed to be more holistic and every nurse should have expertise information of basic mental health problems. (Kokkonen & Wallace 2015.)

It has been found that a person with a chronic disease is more prone to depression (Safren, Gonzalez & Soroundi 2008, 1). Studies show that chronically ill patients have significantly more mental health problems than rest of the population. For instance, people with a cardiac disease have three times more anxiety and depression compared to the other population. (Kokkonen & Wallace 2015.)

Chronic patients have to manage functional limitations and psychosocial changes. Restrictions on free-time and social activities may follow. Coping with daily activities can diminish, earlier retirement may become necessary, financial stress emerges, roles can change, the person’s self-image can be altered, their self-esteem decreased and loss (of some) of their independence can occur. (Avşar & Kaşıkçı 2011, 47.)

4 Aims, purpose and research question

The aim of this study is to utilize existing data to gain an understanding of what kind of psychosocial experiences patients can have when living with inflammatory bowel diseases.

The purpose is to conduct a literature review, collect recent information for nurses and to raise knowledge about the psychosocial experiences patients can have when living with inflammatory bowel diseases.

The research question is:

What kind of *psychosocial experiences* should nurses take into account while working with patients living with inflammatory bowel diseases?

5 Methodology

5.1 Literature review

In this study, existing material and research are utilized to conduct a literature review. A successful literature review summarizes, explains and interprets essential information of a subject and finds new topics to be studied in future (Sulosaari & Kajander-Unkuri 2016, 107; Suhonen, Axelin & Stolt 2016, 9).

The literature review as a method covers a whole study. The aim of a review is to conduct a report, not only to form a theoretical basis for the study, as literature reviews traditionally form. The most commonly used type of review is a descriptive review, also utilized in this thesis. (Sulosaari & Kajander-Unkuri 2016, 107.) The main focus is on peer-reviewed scientific articles. A literature review is a process that includes material collection and a synthesis, shown in a table. A review is less critical towards original publications, which is the weakness of the method according to Suhonen et al. (2016, 9). On the other hand, when only peer-reviewed articles are used, the studies already include a scientific critique. At least two researchers should always be involved in the process (Niela-Vilén and Hamari 2016, 27).

5.2 Article selection process

Two databases were used for the article search: PubMed and CINAHL. Several test searches were carried out to find the best search words. The same terms were used for both databases. For example, when using the search term “psychological”, the databases mainly produced search results debating the phenomenon “Which was first, the psychological symptom or the IBD? Does a psychological problem cause IBD or vice versa?”. Niela-Vilén and Hamari (2016, 27) stated that even if search terms were carefully selected, the result of the database search can nevertheless produce plenty of unnecessary articles. As Niela-Vilén and Hamari (2016, 27) suggest, the inclusion and exclusion criteria were then implemented: first in the topic selection, secondly with abstracts and thirdly by reading the whole texts.

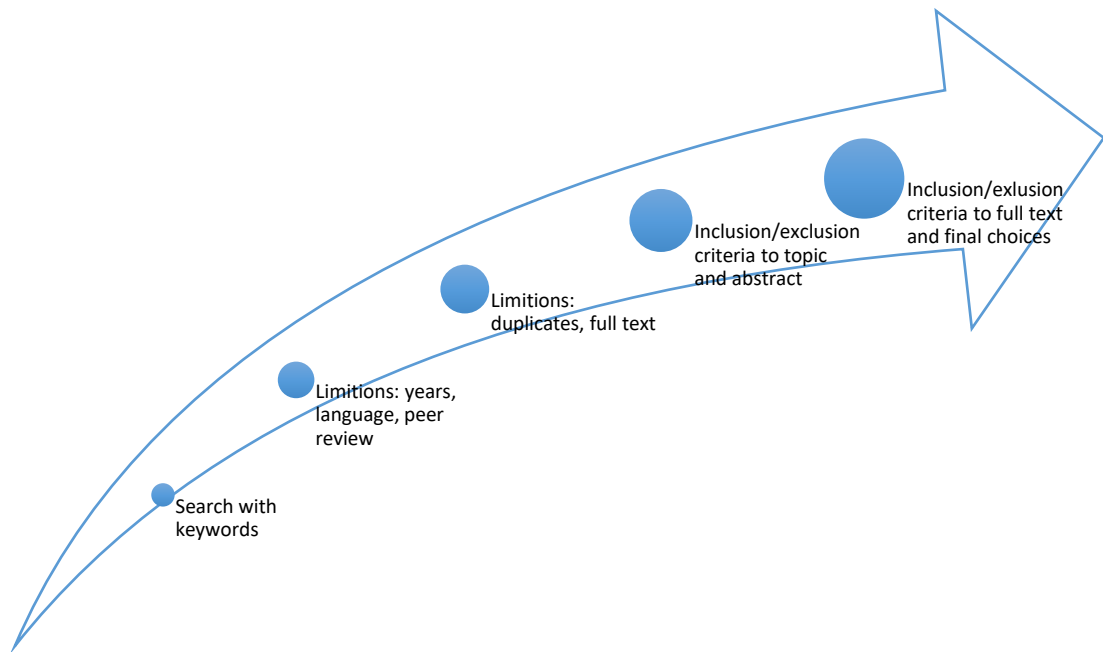


Figure 1 Search process

Figure 1 shows how the search proceeded. The inclusion and exclusion criteria are shown in Figure 2. The search terms were the same in both databases: IBD OR “Inflammatory bowel disease” OR “Colitis ulcerosa” OR “Crohn’s disease” AND Psycho-social. Before making search limitations, CINAHL found 379 articles and PubMed 354 articles. Following this, limitations were used one at a time. First, the publication years were limited to 2005-2017 to discover only recent articles. The language was defined as English. In CINAHL, only peer-reviewed articles were chosen. In PubMed, however, such a choice was impossible and it became obvious that all articles in PubMed were peer-reviewed. Duplicates were removed. When limiting the search to full texts available, the number of results decreased significantly (in CINAHL from 217 to 49 and in PubMed from 221 to 78). After browsing the full texts through, it was evaluated that there is enough qualitative material for the literature review.

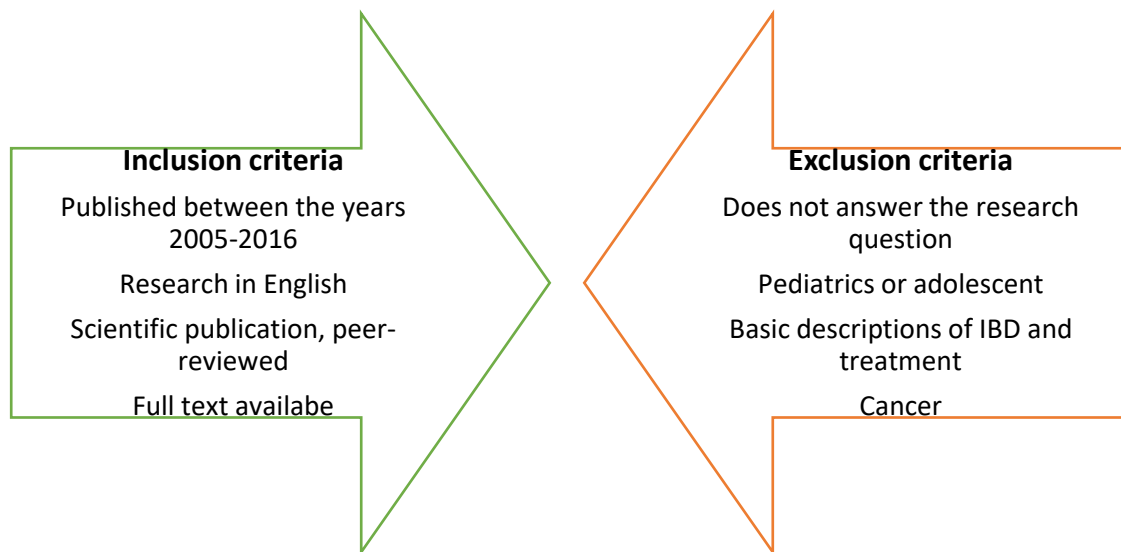


Figure 2 Inclusion and exclusion criteria

The following phase of the search included assessing the results by title using the exclusion criteria (Figure 2). The following subjects were excluded: pediatric/adolescent studies, basic descriptions of IBD and treatments and studies concerning cancer. Studies with no connection to the research question were ruled out. After these exclusions, 21 articles remained in CINAHL and 23 in PubMed. The abstracts of these articles were studied, and again the exclusion criteria were implemented. As a result, 8 articles in CINAHL and 7 articles in PubMed were selected for more careful observation by reading the full texts. Finally, 5 articles in CINAHL and 6 articles in PubMed were chosen for the literature review. The search process is presented in numbers in Figure 3.

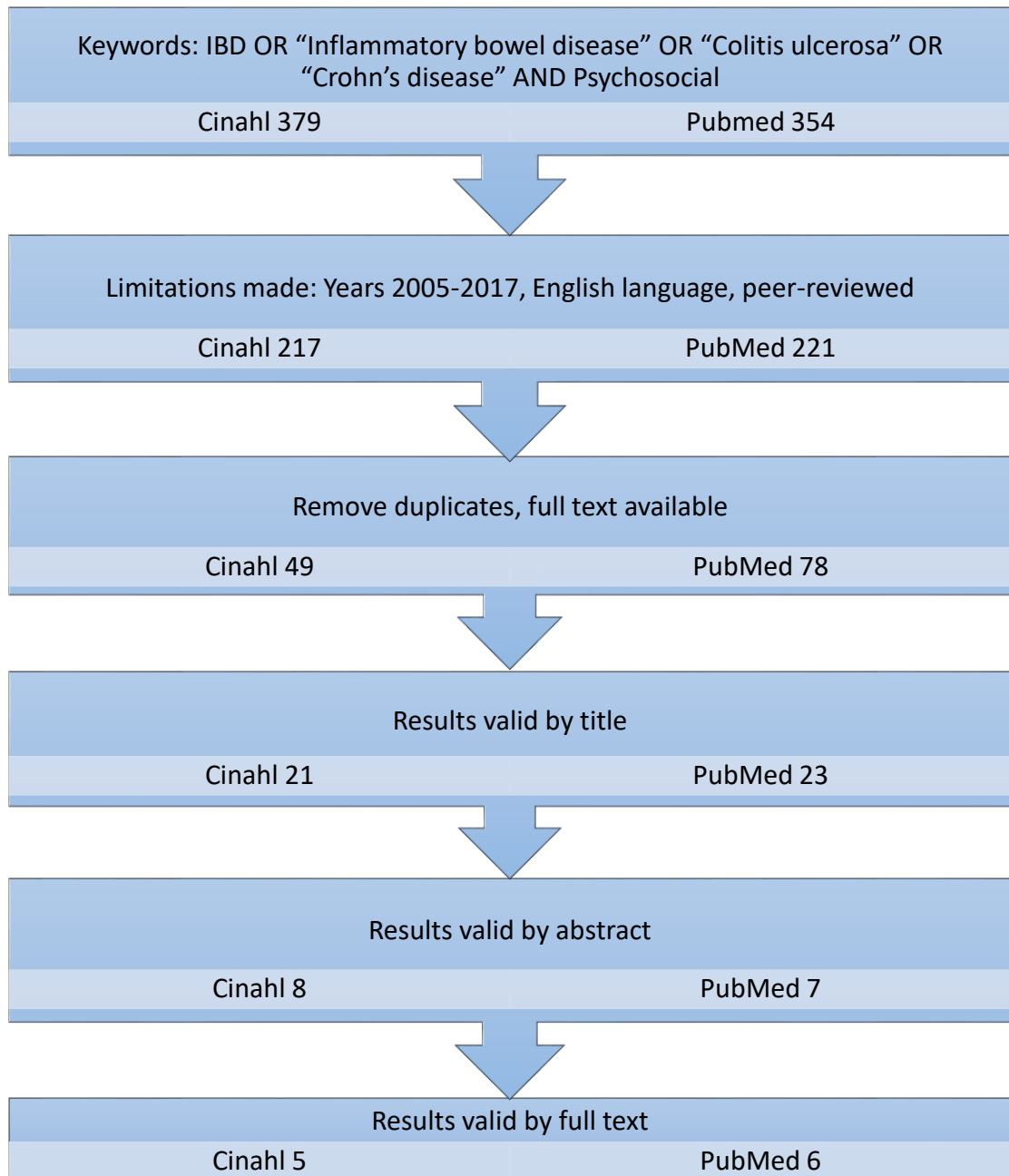


Figure 3 Search process in numbers

5.3 Description and appraisal of data

A total of 11 studies passed the search process: five articles from CINAHL and six from PubMed. The basic publication information, aims, research methods and main results of the articles are presented in Appendix 1. Three studies had been conducted in the USA and three in UK. The remaining five articles were from Portugal, China, Malta, Norway and Japan. The studies were published in 2005 (2), 2009 (1),

2010 (1), 2012 (2), 2014 (2), 2015 (1), 2016 (1) and 2017 (1). The categories of the reports are: two literature reviews, one expert article, five studies based on questionnaires, two studies based on interviews and one mixed method study. Four studies had been conducted from the perspective of health related quality of life (HRQOL). In several studies, a standardized questionnaire of health-related quality of life for IBD patients (IBDQ) had been utilized. Nine articles discussed both UC and CD, two articles concentrated exclusively on UC. In most cases, UC and CD had been studied together, disease-specific studies were quite rare.

Interestingly, only a limited number of studies dealt with the patients' experiences directly. A great number of articles were excluded since they involved pediatric or adolescent patients. In addition, the studies had always been conducted from a negative point of view – any potential positive outcomes of IBD had not even been asked about or reported.

5.4 Analysis of data

A qualitative method of content analysis was used in this thesis. This approach is recommended when the phenomenon is not well known or the knowledge is fragmented (Elo & Kyngäs 2008, 108, 109). Content analysis is used to synthesize and identify dominant findings from published research and make generalizations. A systematic technique is implemented to categorize different themes and possibly to count how often the same themes occur in various studies. The weakness of content analysis is the possibility of being overly reductive and possibly emphasizing less important themes. (Mays, Popay & Pope 2007; 48, 50; Elo & Kyngäs 2008, 109.) Still, this research method enables replication and making valid conclusions from data to their context. Systematic guidelines for data analysis do not exist, but the central point is to discover smaller categories from a large amount of text data. (Elo & Kyngäs 2008, 108-109.) Smaller data pieces are then combined to form general perceptions (Tuomi & Sarajärvi 2009, 95).

Following the guidelines of Elo and Kyngäs (2008, 109-111), the content analysis process for this thesis included three phases: open coding, creating categories and abstraction. Open coding meant making notes or highlights to the texts while reading. Later, the notes were collected and categorized. By using content-descriptive words, each category was named and the categories were combined to larger units if possible. The abstraction phase included formulating a general description or synthesis of the research topic.

In the open coding phase, the articles were read carefully and a color-coding method was used to find different categories, as suggested by Tuomi and Sarajärvi (2008, 109). According to the advice of Tuomi and Sarajärvi (2008, 109-113), the research question led the process so that only valid data was highlighted and listed. In the second phase, the data was processed and clustered to create categories and sub-categories. A specific color marked each category. In the abstraction phase the categories were combined to form theoretical themes and understanding of the phenomenon.

By continuously comparing the similarities and differences of the studies, the theme contents become clearer. The themes were agreed via discussion. The generation of the themes is exemplified in Figure 4.

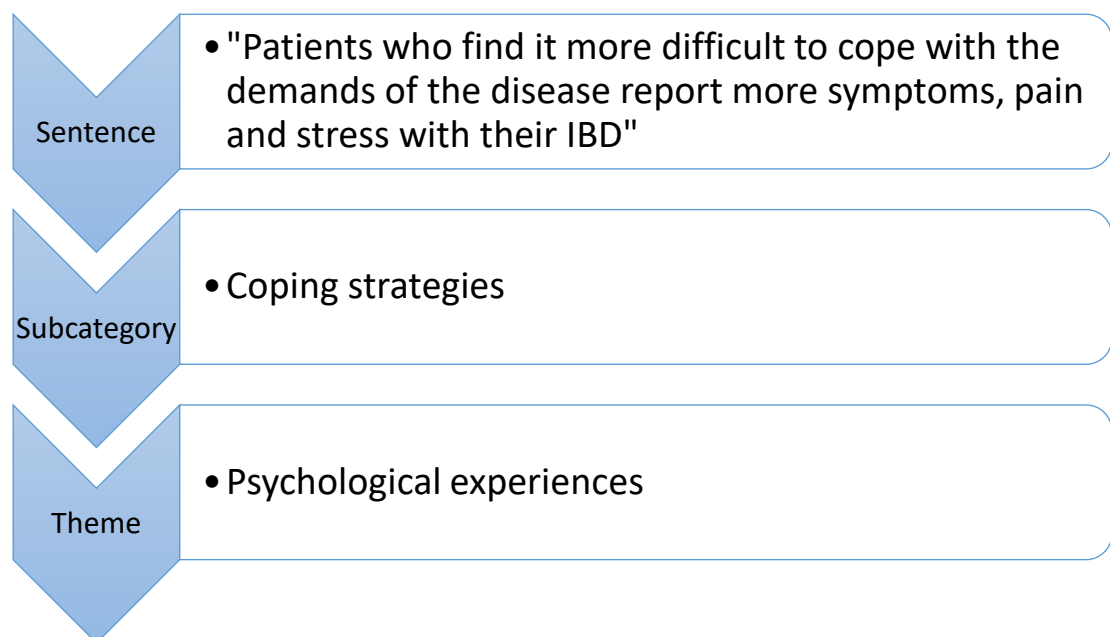


Figure 4 Thematization

6 Results

6.1 Background information

The background information, for example age, gender and education, are studied and slightly different results are obtained in various studies. Magalhães, Castro, Carvalho, Moreira and Cotter (2014, 195) find that female gender is the main predictor of lower quality of life (QOL) in IBD-patients. This is also the result in most studies in Sainsbury & Heatley's (2005, 500) review. According to the study of Zhou, Ren, Irvine and Yang (2010, 86) there is no significant difference according to age, gender or educational level. In addition to these three, Taft, Keefer, Leonhard & Nealon-Woods (2010) find no difference in a comparison between marital status, ethnicity and city size. Tanaka & Kazuma (2005, 71) also discover no difference between genders. According to Sainsbury & Heatley (2005, 501) age can influence to the quality of life. The effects are different in young and elderly patients, for example due to social connections. Faust, Halpern, Danoff-Burg and Cross (2012, 177) explore that older age at diagnosis is a predictor of increased disease activity.

The quality of life is found similar regardless of the patient's disease, UC or CD (Magalhães et al. 2014, 194; Zhou et al. 2010, 83). Faust et al. (2012, 179) and Zhou et al. (2010, 84) consider that the active phase of IBD impacts negatively the health-related quality of life (HrQOL). Faust et al. (2012, 177) state that higher education increases the perceived quality of life, whereas lower education has a negative connection with disease activity, health status and quality of life (Sainsbury & Heatley 2005, 501). Culture has an influence on what sort of worries people have concerning the disease. For example, requiring a surgery or stoma is the greatest fear in many countries, while in other countries the lack of energy, unpredictability of the disease or side effects of the medication may be the greatest concern (O'Toole, Winter & Friedman 2014, 1089-1090).

The main findings are divided into three main themes and into their subcategories. Categorizing is demonstrated in Figure 5.

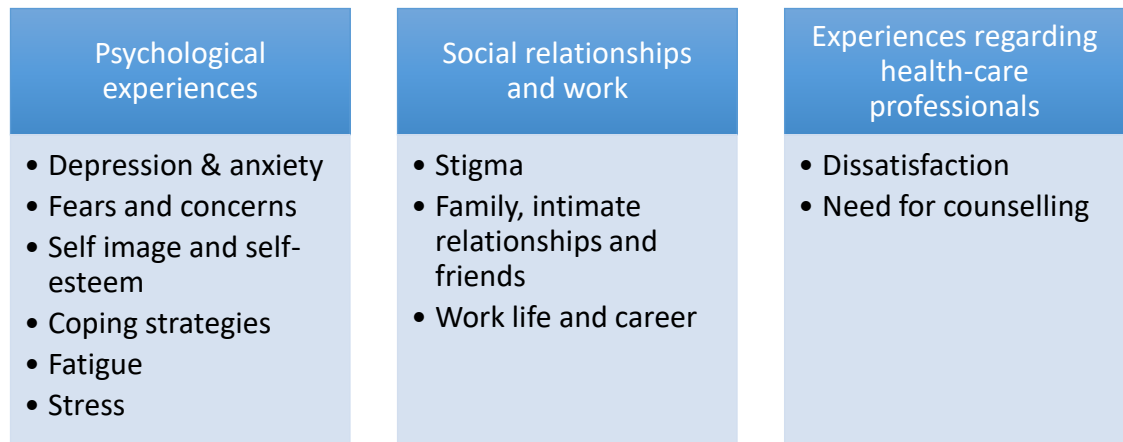


Figure 5 Main themes and subcategories

6.2 Psychological experiences

Among patients, a sense of IBD controlling every aspect of their lives is common (Woodward, Dibley, Coombes, Bellamy, Clark, Czuber-Dochan, Everelm, Kutner, Sturt & Norton 2016, 654; Sainsbury & Heatley 2005, 503). Living with a physical disease is perceived as a difficult phase in life. IBD patients' lifestyle can be restricted as a result of discomfort, pain, unpredictable bowel movements and hospitalization periods. (Sammut, Scerri & Xuereb 2015, 2661-2662; Tanaka & Kazuma 2005, 71.) A range of negative emotions are associated with IBD and mentioned briefly in the studies. The emotions include anger, confusion, guilt, denial, fear, low mood, frustration, devastation, hopelessness and being fed up (Woodward et al. 2016, 654; Sammut et al. 2015, 2662).

Depression and anxiety are identified in nearly all studies (in 8 studies out of 11) in this literature review and they are related to several aspects of life (i.e. Skrautvol & Nåden 2017, 35; Faust et al. 2012, 178; O'Toole et al. 2014, 1090; Woodward et al.

2016, 654). Compared to the general population, IBD patients have a doubled risk of depression (Todorovic 2012, 469). Faust et al. (2012, 178) find that even 49 % of IBD-patients have a high level of anxiety and 26 % suffer from symptoms of depression. CD patients have greater depression and anxiety levels, and possibly because of that, their QOL level is lower than UC patients' (Sainsbury & Heatley 2005, 502). A significant finding is that most (81 %) patients with high depression levels were undergoing an active phase of IBD (Faust et al. 2012, 177). In patients with lower depression symptom levels, only 53 % are in an active phase of the disease. Differences among patients suffering from low or high levels of anxiety are not shown. Faust et al. (2012, 177) mention that their finding is statistically significant but differed from earlier studies. For example, Todorovic (2012, 469) brings out the connection between mood disorders, stress and disease activity. Unpredictability and uncertainty concerning IBD relapses, treatment options with their side effects, surgery and the idea of having a stoma are also reasons for distress (Woodward et al. 2016, 655-656). Lack of social support is found to be a risk factor for depression (Tanaka & Kazuma 2005, 72).

A variety of fears and concerns are reported relating to the illness. Fear of fecal incontinence is an important cause of distress (Woodward et al. 2016, 656). One finding is a fear of cancer before a confirmed IBD-diagnosis (Sammut et al. 2015, 2663). A fear of a lifelong stoma is a common concern (O'Toole et al. 2014, 1090). Fears concerning fertility are also reported (O'Toole et al. 2014, 1087; Sammut et al. 2015, 2663) and women experience fear, anxiety or guilt related to pregnancy. Concerns of the possible harm or passing the illness to the fetus bring negative feelings (Sammut et al. 2015, 2663; Woodward et al. 2016, 655). Similarly, worry about the assumed heredity of the disease and congenital malformations exists among men; their concerns mostly pertains to infertility and the side effects of the medication (O'Toole et al. 2014, 1087). The fear of infertility is more common with women and with CD-patients (O'Toole et al. 2014, 1087). Women seem to have more concerns and worries about their attractiveness and body image. They also worry if they are treated differently due their disease (Magalhães et al. 2014, 195).

Changes of self-image and self-esteem caused by IBD are found distressing (Woodward et al. 2016, 655). Embarrassment or feeling disgusted by the disease symptoms

is common in the study of Woodward et al. (2016, 654). The medication side effects may alter the body image; for example, excessive hair growth and edema may appear. Changes in appearance affect the quality of life negatively (Sammut et al. 2015, 2662). Embarrassing experiences, such as “soiling oneself”, are connected to the altered body image as well – the ability to control bowel movements is changed (Sammut et al. 2015, 2662). Low self-esteem may lead to self-accusations. Feelings of guilt are reported as patients feel that they have got the disease as a result of their own actions, albeit the etiology of the disease is unknown. People blame themselves for eating wrongly or having misused drugs. (Sammut et al. 2015, 2663-2665.)

The effects of different coping strategies are highlighted in the article of Tanaka and Kazuma (2005, 72). More symptoms, such as stress and pain, are reported when the patient finds difficulties to cope with the demands of the disease (Todorovic 2012, 469; Tanaka & Kazuma 2005, 72). Sainsbury and Heatley (2005, 502) note that effective coping strategies help patients in maintaining better health status and satisfaction. Maladaptive strategies, for example avoidance, self-blaming and negative coping methods such as pessimism, lead to lower quality of life. Part of the UC patients try to hide their symptoms and body image changes from others, which causes uncertainty and disturbance in their lives (Sammut et al. 2015, 2665; Woodward et al. 2016, 655). This kind of disengagement greatly affects their quality of life (Faust et al. 2012, 178) and causes emotional distress (Woodward et al. 2016, 654).

Experiences of fatigue, being overwhelmed and burnout are expressed under the demands of the condition. Lack of energy is a source of distress or dejection (Woodward et al. 2016; 654, 656; Skrautvol & Nåden 2017, 34) and strongly affects the perceived quality of life (Magalhães et al. 2014, 194). In Skrautvol’s and Nåden’s (2017, 34) study, patients experience the importance of learning to listen to one’s body and to identify its reactions and limits. With these means, worsening of the disease may be avoided. Tanaka & Kazuma (2005, 71) explore long recovery duration from fatigue after an active disease phase. Social support is found to be a reserve of energy (Tanaka & Kazuma 2005, 71).

Psychological stress is discussed in the study of Skrautvol et Nåden (2017, 34-35). Positive stress creates energy and hope, whereas negative stress causes fatigue and stomach pain. Illnesses of family members, social conflicts or getting into an abusive

social relationships are found to be sources of too much stress. Several patients react to stress with their stomach. Sainsbury and Heatley (2005, 502) and Todorovic (2012, 469) state that stressful life events can exacerbate symptoms and increase disease activity and hereby affect on quality of life. Sainsbury and Heatley (2005, 502) notice, in addition, that stress affects health-seeking behavior and thus patients with high stress levels may be over-represented in clinics.

6.3 Social relationships and work

IBD impacts on social activities and causes distress in social relationships (Woodward et al. 2016, 657) and difficulties in leisure activities (Magalhães et al. 2014, 194). Patients worry that their illness would restrict not only their own, but also their partner's social activities (Woodward et al. 2016, 655). Social withdrawal occurs when a person continuously fears embarrassing situations and starts to restrict or avoid social gatherings, events or spare time activities (Sammur et al. 2015, 2663). It is reported that 68 % of patients have experienced social constraint in some level (Faust et al. 2012).

Experience of stigma is perceived by 84 % of patients in Taft's et al. (2010) research. No differences are found between UC and CD patients' experience levels and the severity is mainly low to moderate level. Principally employers, co-workers and friends create stigmatization, whereas partners, family and healthcare professionals are less stigmatizing. Stigma seems to have a significant negative effect in all the following aspects: treatment adherence, systemic and bowel symptoms, emotional and social functions, depression, anxiety, self-esteem and self-efficacy. Stigma is found to be independent of disease status. (Taft et al. 2010.)

Families and people close to patients and the patient's whole psychosocial environment affect on how strongly the person is suffering (Skrautvol & Nåden 2016, 34). Family and close people occasionally refuse to believe that the symptoms and illness are real, causing feelings of hurt and anger in the patient (i.e. Sammur et al. 2015, 2663; Woodward et al. 2016, 655). It is suggested that lack of emotional support and

little understanding for the difficulty of living with the condition may lead to isolation. Close relationships with friends are positively meaningful and important in coping with the disease (Woodward et al. 2016, 655; Skrautvol & Nåden 2016, 34). The topic of bowel disease is found to be a taboo and a source of distress as patients worry how others would react (Woodward et al. 2016, 655-656).

Intimate relationships are discussed in very few articles and usually quickly passed over. Reduced sexual desire and satisfaction are experienced after receiving the diagnosis of IBD (O'Toole et al. 2014, 1087). Both genders report decreased sexual functioning, decline perceived self-image and challenges with hygiene affecting intimate relationships. Women seem to be more concerned with these issues than men. (Sainsbury & Heatley 2005, 503.) The level of sexual activity, libido, sexual attractiveness and enjoyment of sex are significantly impacted when the disease is active (O'Toole et al. 2014, 1089) and erectile and ejaculatory difficulties occur. Medication may explain some of these problems. Sexual motivation is inhibited due to potential fecal incontinence during sexual intercourse. Since depression is common in the active phase of the disease, it can also contribute to sexual dysfunction. (O'Toole et al. 2014; 1089, 1091.) Symptoms such as pain, increased bowel function and fecal incontinence, as well as abdominal pain during intercourse are found to affect intimate relationships (Sammut et al. 2015, 2663; Sainsbury & Heatley 2005, 503).

The effect of IBD on work life and career are reported in several articles. Sometimes patients find that IBD affects their career development negatively. Magalhães et al. (2014, 195) suggest that the effect is caused by sick leaves and disability pensions. Zhou et al. (2010, 84) discover that patients with full-time work experience significantly better quality of life compared to workers on part or full time sick leave. Self-employed patients have developed special strategies to help them continue working despite the illness (Sammut et al. 2015, 2664). Sammut et al (2015, 2664) came across the fact of patients incurring into a circle of challenges when symptoms of IBD appear. The patients' quality of sleep deteriorates, causing fatigue and diminishing their capacity to work. Subsequently, sick leave is needed. The situation brings changes in the financial situation, causing more worry and stress and allowing the circle of challenges to continue.

Lack of support from co-workers is evidenced (Magalhães et al. 2014, 194-196; Woodward et al. 2016, 655) and it worsens the patient's quality of life (Magalhães et al. 2014, 194-196). Occasionally employers seem to deny the fact that IBD-patients' symptoms are real (Woodward et al. 2016, 655). Isolation and loneliness at work-place are experienced. Nonetheless, sometimes work is re-organized to provide placement close to the toilets and/or working alone. Some patients feel that the arrangement lead to isolation from other employees, while others regard it as a positive investment. (Sammut et al. 2015, 2664.)

6.4 Experiences regarding health-care professionals

Dissatisfaction towards health care professionals is the most frequent cause of distress. Patients feel that doctors do not have sufficient knowledge of the disease or they are underestimating the illness (Sainsbury & Heatley 2005, 504). (Woodward et al. 2016, 655.) Patients report that even though they are in remission, it is possible that they feel sick (Tanaka & Kazuma 2005, 70). Some health care professionals incorrectly still consider IBD symptoms as psychological in nature (Sammut et al. 2015, 2665), causing psychological disturbance and experience of stigma among patients. Sainsbury & Heatley (2005, 501) report patient experiences where insufficient information about the condition is provided, which possibly cause concerns related to disease. Patients find that the focus is excessively on medication, and neither alternative treatments nor changes in lifestyle are taken into consideration (Skrautvol & Nåden 2017, 36).

Counseling is often required on the following topics: being alone, feeling like a burden, impaired sexual capacity and feeling dirty or smelly (O'Toole et al. 2014, 1090). Stress management skills affect the course of the disease positively and can also be practiced in counseling (Todorovic 2012, 469). Sexual dysfunction is not a frequent subject to cover with doctors as it is not seen as a medical problem and patients have no desire to discuss these themes with a doctor of opposite sex. (O'Toole et al. 2014, 1087.) If the patient is heard and allowed to make her or his own decisions, openness is seen to build up new strength (Skrautvol & Nåden 2017, 35). Todorovic (2012, 470)

stresses the role of nurses in instructing, informing and empowering the patients to actively participate in their treatment. This enables the patients to affect their treatment both in long and short term. Social support groups, networks and individual counseling are evidenced to positively impact the quality of life in IBD patients (Sainsbury & Heatley 2005; Faust et al. 2012, 180). Faust et al. (2012, 180) remind the health care professionals that they should assess the coping styles of the patient, since the effects of poor coping styles are evidenced.

7 Discussion, evaluation and ethics & conclusion

7.1 Discussion

The aim of this literature review was to utilize existing data to gain understanding of what kind of psychosocial experiences patients can have when living with inflammatory bowel diseases. The information collected for this thesis was meant to help nurses in their work with IBD-patients. Barelló et al. (2013, 559) state that the studies are partly fragmented and contradictory, which was found to be true also in this thesis. This was because the information had been collected using different methods and was difficult to compare.

The scope of background information collected and its effects seem to vary from study to study. Still some observations, such as the influence of gender, can be useful. Women seemed to be more sensitive to changes caused by IBD (Magalhães et al. 2014, 195; Sainsbury & Heatley's 2005, 500). One interesting finding was that the potential positive experiences of IBD patients had not been considered at all. It was found from other sources that the IBD diagnosis can sometimes be a relief, since patient may have been afraid of cancer (Gillian 2005). A chronic illness can also, after some time, make people stronger as individuals and raise their self-knowledge and awareness of life's limitations.

As IBD is becoming a common public health problem in Finland (Färkkilä 2014), it must be repeated that IBD does not necessarily cause visible symptoms. Despite this, a patient's feelings and pain experienced are real. Incorrect assumptions of the etiology of the IBD still exist among nurses, even though the cause of the disease is unknown. It should be noticed that patients do not obtain IBD because of psychological reasons or intentionally cause the disease for themselves (Sammur et al. 2015, 2663-2665).

This review shows that IBD affects life in multiple ways and comprehensively (i.e Woodward et al. 2016, 654; Sainsbury & Heatley 2005, 503). The main findings in this study were divided into three themes and their subcategories (Figure 5). The themes are psychological experiences, social relationships and work; and experiences towards health care professionals.

The psychological experiences theme appeared to have six subcategories. Depression and anxiety were the major finding as IBD patients have a great risk to experience depression and/or anxiety (i.e. Skrautvol & Nåden 2017, 35; Faust et al. 2012, 178; O'Toole et al. 2014, 1090; Woodward et al. 2016, 654). According to one study, the active phase of IBD especially is a major risk to develop high depression levels (Faust et al. 2012, 177). Depression and anxiety are definitely common in IBD-patients and the easiness of measuring these problems can be a reason why they become emphasized in this study. Several well-validated and standardized questionnaires concerning anxiety and depression exist. They provide practical and trustworthy tools for diagnosis and have been widely used in the studies included in this literature review.

The second subcategory was IBD-related fears. Patients were afraid of how IBD might affect their body (O'Toole et al. 2014, 1090), for example due to stoma surgery, changes in body image or its functions. Another major concern was if IBD could cause physical harm to future children, especially for the fetus (Sammur et al. 2015, 2663; Woodward et al. 2016, 655). Multiple fears seem to relate to the future – patients worry about matters that might happen in future but they are less concerned of their current situation.

Effects on self-image and self-esteem formed the third subcategory. IBD-related symptoms, such as inability to control the bowel, was experienced as shameful and disgusting, which affects the patient's self-esteem (Woodward et al. 2016, 654). Medication can change the physical appearance causing problems with self-esteem, too (Sammur et al. 2015, 2662). One visible sign of low self-esteem is blaming oneself for the disease (Sammur et al. 2015, 2663-2665). Having a disease in such a sensitive and embarrassing area as bowel can have a great impact on self-image and self-esteem. Impaired self-esteem and great negative emotional experiences certainly affect the quality of life and should be recognized by healthcare personnel.

Use of different coping strategies was the fourth subcategory. Acceptance of the disease and using effective coping strategies seem to have a positive impact on symptom activity, whereas negative attitude and use of ineffective coping strategies worsens the state. (i.e Todorovic 2012, 469; Tanaka & Kazuma 2005, 72; Sammur et al. 2015, 2665; Woodward et al. 2016, 655.) The disease and its course cannot be influenced, but it is important to provide proper guidance on how to cope with this fact.

Patients should concentrate on issues that they are able to affect and try to accept the ones they cannot change. Futile attempt to control the disease lead to disappointment and impact the daily living negatively.

Severe fatigue, which is quite common, formed the fifth subcategory. Lack of energy affect the quality of life and could cause distress or dejection (Woodward et al. 2016; 654, 656; Skrautvol & Nåden 2017, 34; Magalhães et al. 2014, 194). Good self-knowledge was important in preventing overtiredness (Skrautvol's & Nåden's 2017, 34). The recovery times are long (Tanaka & Kazuma 2005, 71), which should be noticed among nurses during rehabilitation. Fatigue may be underestimated or misinterpreted as laziness. Fatigue, however, can be directly caused by IBD as one of the main symptoms. It can also be a consequence of depression or other psychological factors. In the studies explored for this literature review, the causes of fatigue had not been specified. In any case, understanding and supportive guidance help the patient learn the limits of their body and mind. Fatigue is a subjective experience and should always be observed individually. Moreover, outside hospitals, sufficient assistance should be provided to help patients cope with everyday living.

The sixth subcategory in psychological experiences theme was stress. In four of the articles, stress was found to directly affect the experienced IBD symptoms (Sainsbury & Heatley 2005, 502; Todorovic 2012, 469; Skrautvol & Nåden 2017, 34-35). Although stress is a minor category in this thesis, it is still strongly linked with all the other categories; stress can, for example, cause physical stomach symptoms even in healthy people. It can be speculated that patients with more severe IBD symptoms may be more likely to become stressed and that stressed patients experience more symptoms. It can also be assumed that stress lengthens the treatment time in the active state IBD.

Social relationships and work were the second main theme, with three subcategories. The first of them was stigma. The articles contain few references to stigma, although it seems to affect IBD patient's life in multiple ways (Taft et al. 2010; Sainsbury & Heatley 2005, 501; O'Toole et al. 2014, 1087). Taft et al. (2010) reported a high percentage of patients with experienced stigma, mainly connected with employers, co-workers and friends. Stigma levels are lower with the family, partner and healthcare professionals (Taft et al. 2010). Is the experience of being stigmatized real

or only an individual's perception? Would it lessen the stigma if there was more information about IBD, discussed more openly? This might help people understand the illness better and eliminate the stigma.

The second subcategory in social relationships and work was the impact of IBD on family, intimate relationships and friends. The psychosocial environment affects the patient's level of suffering (Woodward et al. 2016, 655; Skrautvol & Nåden 2016, 34), but IBD seems to be a difficult topic to talk about and patients may feel that they are not properly understood or supported (Woodward et al. 2016, 655-656; Sammut et al. 2015, 2663). As with stigma, it seems that receiving sufficient information and open discussion can be the key to coping with the illness. If families and friends have sufficient knowledge of the disease, they can support the patient and feel that they play an important role in management of the illness.

Information about the impact of IBD on sexuality was only discussed properly by O'Toole et al. (2004) and mentioned shortly in papers of Sammut et al. (2015) and Sainsbury & Heatley (2005). Both women and men report multiple consequences in their sexuality due to IBD (O'Toole et al. 2004, 1089; Sainsbury & Heatley 2005, 503). A large amount of experienced fears seem to be associated with sexuality (see chapter 6.2). Sexuality is a part of life and should definitely be prominent in conversations and guidance with nurses. The subject can be experienced as a taboo and shamed topic nevertheless it is important and relieving, when properly covered.

The effect of IBD on work life and career formed the third subcategory in this thesis. Sick leaves and disability pensions seemed to affect the quality of life, career fulfillment and the economic status of the patient (Magalhães et al. 2014, 195; Zhou et al. 2010, 84). Patients experienced the support from employers and co-workers as insufficient or unsuitable (Magalhães et al. 2014, 194-196; Woodward et al. 2016, 655; Sammut et al. 2015, 2664). Could experienced lack of support from co-workers and employers only be a result of poor knowledge of the disease? Some people at work may try to help but the IBD patients may misinterpret it. As mentioned before, information and open discussion could be useful at work place, too. Telling about the disease in an open manner might decrease misunderstandings and help find proper ways to support the patient at work. Although the idea was not discussed in any of

the studies, it is possible that patients also experience a fear of unemployment – are IBD-patients afraid of losing their job if they openly talk about their disease?

The first subcategory concerning health care professionals was dissatisfaction. Patients faced that doctors had insufficient knowledge about the disease and the condition of the patient. Patients also experienced that doctors did not believe the symptoms (Sainsbury & Heatley 2005, 504). (Woodward et al. 2016, 655.) It was noticed that studies mainly focus on the doctor-patient-relationship, whereas the nurses' role is not highlighted. In some countries, doctors have a greater role in the IBD patients' treatment and guidance process, whereas in Finland nurses have more responsibilities. The nurse's role is emphasized when a patient is not able to speak openly with the doctor. It is proposed that nurses should have closer contact with patients to facilitate talking about difficult issues. The nurse's more active role might reduce dissatisfaction among patients.

The second subcategory was IBD patients' need for counseling. According to O'Toole et al. (2014, 1090), often-required counseling areas include experiences of being alone, being a burden and being sexually incapable. The same feelings were discussed earlier in this literature review as psychosocial findings (see chapters 6.2 & 6.3). It seems that these findings recur. The experiences strongly affect the patients' quality of life and are the themes that patients seek support for. The nurse's role is to empower patients to actively participate in decision-making and that way strengthen their commitment to treatment (Sainsbury & Heatley 2005, 504; Faust et al. 2012, 180). Support from close people has been found to be an advantage for IBD-patients (Woodward et al. 2016, 655; Skrautvol & Nåden 2016, 34), nurses should emphasize these relationships and provide opportunities and advice on how to utilize them. Peer support groups were an important channel for patients to share their experiences with others in same situation (Sainsbury & Heatley 2005, 504; Faust et al. 2012, 180). Nurses should provide information and encourage patients to participate in these group discussions.

7.2 Evaluation and ethics

Scientific research has several norms and guidelines to follow. Generally, it is required that investigators identify and report the methods of study. A critical attitude is emphasized in every phase of the work, in addition to being prepared to redefine the methods when necessary. A well-planned and organized method is expected, as well as open reporting of the stages of the work. Clarity and simplicity are strived for and ethical question should be pondered continuously. (Hirsjärvi, Remes & Sajavaara 2004, 23-25.) Especially in nursing field, ethical questions are important and significantly guide the progress of a thesis. The resources allocated for writing a thesis are usually not sufficient to apply permission to implement enquiries for patient groups or to make statistical analysis based on patient records; the authorization usually takes plenty of time and effort. The research method for this thesis was chosen, because it did not require specific permissions, but allowed the authors to use the time resources available directly on implementing the research. A literature review met these criteria.

Hirsjärvi et al. (2004, 25-28) emphasize three ethical evaluation areas. Firstly, topic selection should be considered: does something or someone, for example money or a trend, direct the selection of the topic? Secondly, one should ask how the target group has been treated to avoid manipulation. Thirdly, striving for honesty must be observed throughout the study. This means, for instance, that plagiarism must be avoided in every form and the contribution of other researchers should never be underrated. The results should not be embellished, the reporting must not be misleading and deficiencies should be stated. (Hirsjärvi et al. 2004, 25-28.)

The reliability of the research means that there is a possibility to repeat the research and that the results are similar (Hirsjärvi et al. 2004, 216). The literature research process in this thesis has been explained in detail to enable repetition of the research. The data search implementation and criteria for inclusion and exclusion have been described carefully; in addition, the data analysis process has been clearly described. Therefore, this research can be regarded as reliable. There is a possibility that, if repeated, the study themes could emerge differently. This is the potential

weakness when using content analysis. The relations of different themes and subcategories may vary between researchers. There were three researchers in this study and the categorization was reached through discussion, which increases the reliability of this thesis.

Validity is used to evaluate how the research method succeeds - does the research method measure exactly what is supposed to measure? Especially in qualitative research, it is essential that the research process is described precisely (Hirsjärvi et al. 2004, 216-217). In this thesis, the research question was formulated as unambiguously as possible. Continuous conversation was maintained when making decisions on how the article searches should be performed and what were the criteria in selecting material. These criteria have been shown clearly in this paper. Multiple databases were used and only valid articles were chosen. This thesis was conducted as teamwork, which ensures that possible bias and personal opinions were ruled out. Every reference was discussed by at least two researchers and the third person considered if the written outcome was acceptable. The outcome represents an accurate response to the research question.

7.3 Conclusions and further studies

It seems that the effects of inflammatory bowel diseases can be indirect or direct. For example, experiences of isolation are not directly caused by IBD. During an active phase of the disease, a patient may develop depression, which causes fatigue leading to decreased social life and risk of isolation. Another example of such a negative circle is perceived pain and abdominal discomfort reducing the will of to socialize, which can again lead to isolation. The issues are strongly linked together, one affecting to another.

Interestingly, the study conducted in China (Zhou et al. 2010), gave divergent results concerning IBD patients' quality of life. The study is singular in that it emphasizes the meaning of work in relation to the quality of life. It would be interesting to investigate further if this difference is caused by culture and if it could be discovered in

other Asian cultures. Altogether, the connections between IBD and culture have not been studied.

Another subject requiring more research is sexuality among IBD-patients. The lack of research is surprising, as sexuality is not a taboo anymore, as it still was in recent history. Sexuality is an important part of life and affects people's wellbeing in several ways. Finally, stigmatization seems to be a very common experience among IBD patients. It is curious that it has not been studied more. Nurses need valid information and knowledge to be capable to support patients in seeking relief from the perceived stigma. This would be a valuable topic for further research.

As a conclusion: this literature review implicates that there is a need to raise awareness about IBD patients' experiences amongst nurses. It seems evident that the psychosocial consequences of IBD are extensive and it is recommended that nurses look at IBD as a wide-ranging disease. Psychosocial experiences not only affect the patient's quality of life but also have an effect on disease activity. Nurses should assess the coping strategies of their patients and guide them towards coping with the disease. Careful screening of social problems, fatigue and stress levels should likewise be implemented continually to prevent unnecessary suffering.

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Appendices

Appendix 1 Basic information of the chosen research articles

Authors & country	Article name	Publication	Aim and purpose	Research method & sample	Essential outcomes
Faust, A. H., Halpern, L. F., Danoff-Burg, S. & Cross, R. K. USA	Psychosocial Factors Contributing to Inflammatory Bowel Disease Activity and Health-Related Quality of Life.	Gastroenterology & Hepatology, 2012. 8(3), 173-181.	To examine the contributions of coping and social constraint to disease activity and HRQOL and to examine group differences in disease activity and HRQOL between patients with high versus low anxiety or depression symptoms in adults with IBD.	Retrospective analysis of 6 questionnaire data: Short IBDQ, COPE questionnaire, Hospital anxiety and Depression Scale, Social Constraint Questionnaire. 80 patients.	Social constraint, disengagement coping, anxiety symptoms, and depression symptoms were inversely correlated with HRQOL. Disengagement coping was positively correlated with disease activity. Smokers had significantly worse HRQOL.
Magalhães, J., De Castro, F. D., Carvalho, P. B., Moreira, M. J. & Cotter, J. Portugal	Quality of life in patients with inflammatory bowel disease: importance of clinical, demographic and psychosocial factors.	Arquivos de Gastroenterologia. 2014 (1), 3, 192-197.	To analyze the relationship between clinical and sociodemographic factors and quality of life in IBD patients.	IBDQ-32 and sociodemographic and clinical data questionnaires. 150 patients, 92 with CD and 58 with UC	IBDQ-32 scores were significantly lower in female patients, patients with an individual perception of a lower co-workers support and career fulfillment, patients requiring psychological support and pharmacological treatment for anxiety or depression. Predictors of impaired HRQOL: female gender and the perception of a lower co-workers support and career fulfillment.

Authors & country	Article name	Publication	Aim and purpose	Research method & sample	Essential outcomes
O'Toole, A., Winter, D. & Friedman, S. USA	Review article: the psychosexual impact of inflammatory bowel disease in male patients	Alimentary Pharmacology and Therapeutics 2014. 39, 1085-1094.	To summarize the current literature on sexual function in male patients with IBD.	Literature review, 12 papers.	IBD affects in sexual dysfunction, desire and satisfaction. Disease activity relates to impaired psychological function, and is the risk factor for sexual problems.
Sainsbury, A. & Heatley R. V. UK	Review article: psychosocial factors in the quality of life of patients with inflammatory bowel disease. 2005.	Alimentary Pharmacology and Therapeutics 2005. 21, 499-508.	To review the psychosocial factors affecting quality of life in patients with IBD.	Literature review, 107 papers.	Important psychosocial factors are gender, socioeconomic status, ethnicity and perceived stress.
Sammut, J., Scerri, J. & Borg Xuereb, R. Malta	The lived experience of adults with ulcerative colitis.	Journal of Clinical Nursing. 2015. 24, 2659-2667.	To explore the lived experiences of adults with UC.	An exploratory, qualitative, phenomenological, design was used. Method: Semi-structured interviews. 10 adult UC patients in Malta	Three super-ordinate themes emerged from the analysis: 'living with physical discomfort', 'emotional turmoil in living the experience' and 'social interactions'.

Authors & country	Article name	Publication	Aim and purpose	Research method & sample	Essential outcomes
Skrautvol, K. & Nåden, D. Norway	Tolerance Limits, Self-understanding, and Stress Resilience in Integrative Recovery of Inflammatory Bowel Disease.	Holistic Nursing Practice. 2017, 31(1), 30-41.	To examine patients' experiences with psychosocial stress with IBD, and how they try to achieve better health and wellness.	Hermeneutic approach, Interviews. 13 adults in Norway, age 18-45. 3 male, 10 female participants.	(1) Understanding limits in embodied tolerance, (2) Restoring balance is creating a new equilibrium, and (3) Creating resilience through integrative care.
Taft, T. H., Keefer, L., Leonhard, C. & Nealon-Woods, M. USA	Impact of Perceived Stigma on Inflammatory Bowel Disease Patient Outcomes	Inflammatory Bowel Diseases, 2009. 15(8), 1224-32	To identify the role and impact of perceived stigma in IBD.	Cross-sectional correlational research design. Several questionnaires: IBDQ, The Medication Taking Behavior Scale (MTBS), The Rosenberg Self-Esteem Scale (RSES), etc. 211 patients, 55 with UC and 156 with CD.	84 % of participants reported perceived stigma. Stigma affects in HRQL, psychological distress, medication adherence, self-esteem and self-efficacy
Tanaka, M. & Kazuma, K. Japan	Ulcerative colitis: factors affecting difficulties of life and psychological well being of patients in remission.	Journal of Clinical Nursing, 2005. 14, 65-73.	To elucidate factors that influence perception of difficulties of life and psychological well being of patients with UC in remission.	Questionnaire survey: Perception of difficulties of life (developed by authors), Japanese version of POMS (65-item profile of mood states), physical condition and background characteristics. 72 outpatients with UC in remission. 40 male, 32 female.	Despite being in remission, "decline of vitality or vigour" was perceived. In the presence of IBS-like symptoms "difficulties of life in society", "difficulties concerned with bowel movements" were high. When the emotive coping score was high, psychological wellbeing was not fine.

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Todorovic, V. UK	Providing holistic support for patients with inflammatory bowel disease.	British Journal of Community Nursing. 2012, 17(10), 466-472.	Scientific article, peer reviewed.	No data available	Community nurse's role is important as information giver and supporter for the patients.
Woodward, S., Dibley, L., Coombes, S., Bellamy, A., Clark, C., Czuber-Dochan, W., Everelm, L., Kutner, S., Sturt, J. & Norton, C. UK	Identifying disease-specific distress in patients with inflammatory bowel disease.	British Journal of Nursing. 2016 (25), 12, 649-660.	To determine the presence of IBD distress to inform development of a scale for assessing the phenomenon.	Mixed methods study: Secondary analysis of existing data, focus group discussion, survey for health professionals	Five IBD-distress themes were identified: emotional distress; healthcare-related distress; interpersonal/social distress; treatment-related distress; and symptom-related distress
Zhou, Y., Ren, W., Irvine, E. J. & Yang, D. China	Assessing health-related quality of life in patients with inflammatory bowel disease in Zhejiang, China.	Journal of Clinical Nursing. 2010, 19, 79-88.	To assess HrQOL in patients with IBD in Zhejiang, Mainland China	IBDQ Chinese version, Short-Form-36. 92 patients, 52 with UC and 40 with CD.	No significant difference between UC and CD. Active disease leads to lower scores in Short-Form-36. Disease activity and employment status explained HrQOL variations.