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Athletes with inflammatory bowel diseases and their experiences of nursing guidance

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Abstract

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Inflammatory bowel disease (IBD) is a collective title for Crohn's disease and ulcerative colitis. The number of people suffering from these chronic diseases has increased rapidly in the past years. The purpose of this thesis was to describe Finnish athletes' experiences of IBD-nursing guidance by illustrating the content of the guidance received. The aim of the thesis was to discover new information to develop IBD-nursing guidance in Finland.

Physical activity affects mental and physical health in positive ways and exercise has also been proved to have disease preventive effects. However, the relation between IBD-symptoms and physical activity has not yet been broadly studied and so far IBD-patients have received insufficient and unclear guidance on physical activity. Athletes were interviewed for this study to find out how they have experienced the current IBD-nursing guidance and has their active way of life been taken into account in it.

Qualitative data was collected by using theme interview as a method. Five male athletes were individually interviewed about their experiences of IBD-nursing guidance. Interviews were made as video calls and four themes were covered in each one of them. Four main categories were produced from the data by using inductive content analysis.

The findings disclose that the athletes were satisfied with overall guidance apart from the bad experiences at diagnostic stage. The physically stressing lifestyle of athletes was not taken into consideration and the athletes wished that nutritional guidance was emphasized more in IBD-nursing guidance. Peer support and independent research proved to be important in getting information about the disease.

Based on the findings it is suggested that all IBD-patients would meet an IBD-specialized nurse after the diagnosis to discuss the disease. The background and athletic lifestyle of the patients should also be taken better into account in guidance.

Keywords: inflammatory bowel diseases, Crohn's disease, Colitis ulcerosa, nursing guidance, athlete

Laurea Ammattikorkeakoulu **Tiivistelmä**
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Opinnäytetyö

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Tulehduksellista suolistosairautta sairastavien urheilijoiden kokemuksia hoidonohjauksesta

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Tulehdukselliset suolistosairaudet (IBD) on yhteinen nimi Crohnin taudille ja haavaiselle paksusuolentulehdukselle. Näitä kroonisia sairauksia sairastavien määrä on kasvanut nopeasti viime vuosina. Tämän opinnäytetyön tarkoituksena oli kuvailla suomalaisten urheilijoiden kokemuksia tulehduksellisten suolistosairauksien hoidonohjauksesta havainnollistamalla saadun ohjauksen sisältöä. Työn tavoitteena oli löytää uutta tietoa IBD-hoidonohjauksen kehittämiseksi Suomessa.

Fyysinen aktiivisuus vaikuttaa positiivisesti psyykkiseen ja fyysiseen terveyteen ja liikunnalla on todettu olevan myös sairauksia ennaltaehkäiseviä vaikutuksia. Siitä huolimatta tulehduksellisten suolistosairauksien oireiden ja fyysisen aktiivisuuden välistä yhteyttä ei ole vielä paljon tutkittu ja tähän mennessä IBD-potilaat ovat saaneet puutteellista ja epäselvää ohjausta fyysiseen aktiivisuuteen liittyen. Urheilijoita haastattelemalla selvitettiin, millaisena he ovat kokeneet nykyisen tulehduksellisten suolistosairauksien hoidonohjauksen ja onko heidän aktiivista elämäntapansa otettu huomioon siinä.

Kvalitatiivinen aineisto kerättiin teemahaastattelumetodia käyttäen. Viittä miesurheilijaa haastateltiin yksittäin koskien heidän kokemuksiaan tulehduksellisten suolistosairauksien hoidonohjauksesta. Haastattelut tehtiin videopuheluina ja jokaisessa käytiin läpi neljä teemaa. Aineistosta muodostettiin neljä pääkategoriaa induktiivista sisällönanalyysiä käyttäen.

Tuloksista käy ilmi, että urheilijat olivat kokonaisuudessaan tyytyväisiä saamaansa ohjaukseen lukuun ottamatta diagnoosivaiheen huonoja kokemuksia. Urheilijoiden fyysisesti kuormittavaa elämäntyyliä ei ollut otettu huomioon ja urheilijoiden toiveena oli, että ruokavalioon liittyvää ohjausta painotettaisiin enemmän. Vertaistuki ja itsenäinen tiedonhaku osoittautuivat tärkeiksi tavoiksi saada tietoa sairaudesta.

Tulosten perustella voidaan ehdottaa, että kaikki IBD-potilaat tapaisivat sairauteen erikoistuneen sairaanhoitajan diagnoosin jälkeen, jotta he voisivat keskustella sairaudesta. Myös potilaiden tausta ja urheilullinen elämäntapa tulisi huomioida paremmin hoidonohjauksessa.

Avainsanat: tulehdukselliset suolistosairaudet, Crohnin tauti, Colitis ulcerosa, hoidonohjaus, urheilija

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1 Introduction

Inflammatory bowel diseases (IBD) are chronic diseases in the alimentary tract. IBD is a collective title for Crohn's disease and Colitis ulcerosa. The various disease symptoms can make everyday life difficult. Studying IBD is current as the amount of Finns suffering from inflammatory bowel diseases has increased rapidly in the past 25 years, now concerning over 40 000 people. (Färkkilä 2014.) The pathogen for inflammatory bowel diseases remains unknown (Färkkilä 2007), and no prevention work can be done. The increasing amount of IBD-patients, who are often young adults, brings challenges in organizing the healthcare. With limited resources it is important that IBD-nursing guidance is functional.

Physical activity has several redeeming features for mental and physical health and disease prevention, but so far the relation of IBD and physical activity has not been studied broadly. Previous studies indicate that IBD-patients would be likely to benefit from physical activity just like anyone else (DeFilippis et al. 2015). However, it seems that healthcare professionals have been giving them unclear guidance on proper amounts of exercising (Nathan, Norton, Czuber-Dochan & Forbes 2013). Considering the positive effects of physical activity, it appeared as important to study, how it is taken into account in Finnish IBD-nursing guidance.

In Finland there are several top athletes, who have come public about suffering from IBD (Helsingin Sanomat 2015; Iltalehti 2015; Yle Akuutti 2009). Despite the disease they have managed to compete on national or even international level in sports. It was considered that competitive athletes if anyone should have received guidance on combining IBD and physical activity. Therefore, they were chosen as the group of informants. The physical stress on their bodies and the great energy consumption differs them from other IBD-patients, which should be taken into account in today's holistic nursing care and guidance.

The purpose of this thesis is to describe Finnish athletes' experiences of IBD-nursing guidance, therefore, qualitative research method was chosen. Athletes participated in theme interviews and the data gathered was analyzed with inductive content analysis. The findings show that athletes are content with overall guidance, but guidance at diagnostic stage as well as nutritional and sports related guidance need to be improved.

The aim of this thesis is to discover new information to develop IBD-nursing guidance in Finland. No previous studies on Finnish athletes' experiences of nursing guidance were found. Therefore, this thesis presents new information about IBD-guidance. On top of that, it has been agreed that the final thesis will be sent to three gastroenterology outpatients clinics of three different University Hospitals in Finland to help them improve IBD-nursing guidance.

Participants of this study were professional Finnish athletes, who had been competing on a national or international level in sports when diagnosed with IBD. Thus, this study focuses on one of the sub-groups of people suffering from IBD. Coherent but individualized nursing guidance is needed to help the patients to continue with their physically active lifestyle or even with world-class sports. The findings provide beneficial information for coaches and other people working with physically active IBD-patients, too.

2 Inflammatory bowel diseases

Two chronic diseases of gastrointestinal tract, Crohn's disease (CD) and Colitis ulcerosa (CU) form inflammatory bowel diseases (IBD) (Bettany & Gardiner 2013). Recognizing these two diseases from each other can be challenging, but there is a slight difference in which part of the body the disease affects. In Colitis ulcerosa large intestine and rectum are damaged whereas in Crohn's the diseased area is larger and more severe. The disease can lie from the mouth to the anus. (Crohn ja Colitis ry 2016.)

Gender does not have an effect for the onset of becoming ill with inflammatory bowel disease (Amplo & Nelson 2009). The peak of IBD appears to be during adolescence and first years of adulthood. Nevertheless, older people can also fall ill with IBD. (Bettany & Gardiner 2013.) Inflammatory bowel disease can be suspected based on specific symptoms. In the beginning symptoms might not be aggressive and can remain undetected. For this reason, diagnosis is gotten usually after symptoms have lasted for a long time and situation is worsen (Käypä hoito 2011). IBD is diagnosed by examining biopsy specimen and performing endoscopy. Symptoms' severity and density can vary and are slightly different in Crohn's disease and Colitis ulcerosa. However, diarrhea with or without blood, stomachache, weight lost, increased need of void the bowels, fatigue, fever, anemia, pain in joints and changes in skin or eyes are common symptoms that appear first. Not all symptoms mentioned belong to both diseases. (Crohn ja Colitis ry 2016.)

Colitis ulcerosa and Crohn's disease are both incurable diseases but symptoms can be eased. Treatment is planned individually depending on the disease's characteristic features. Remission and diminishing symptoms after diagnosis are aimed either with continuous medication treatment or operating part of the gastrointestinal tract. Almost every IBD-patient's primary treatment is pharmacological therapy. Before the medication is given the health care professionals have to know the details of the individual's condition; when the disease was diagnosed, how extensive and where exactly it is located, what is the prognosis and is the disease still active or has remission been reached. It is also common to be treated with both surgery and pharmacological therapy. (Bettany & Gardiner 2013). Hospitalization is often not required unless complications emerge during the acute phase of the disease and the patient cannot be treated at home (Färkkilä 2015). The knowledge of dieticians can be utilized when treating IBD since they can better inform the patient how nutrition can ease or worsen the symptoms of IBD. They can also make sure that deficiencies are not being comprised for a patient suffering from IBD. (Bettany & Gardiner 2013.) The risk of being diagnosed with colon cancer is remarkably increased with patients with inflammatory bowel diseases. Ten years after being diagnosed with either CD or CU follow-up appointments will be organized more often than previously due to the risk factor. (Mäkinen 2012.)

In case symptoms of IBD are constant and not treated early enough they can form severe or possible fatal situations for individual. Thus early recognition and monitoring are crucial. (Amplo & Nelson 2009.) Ultimate goal is to maintain clinical remission as long as possible, to live symptom-free life without complications and to be able to live as normal life as possible regardless of the chronic disease (Bettany & Gardiner 2013; Hogan 2011).

There are no prevention methods for either of the chronic diseases. The amount of inflammatory bowel diseases seems to be increasing all over the world from children to adults, also in Finland. According to Crohn and Colitis association (2016) nearly 45 000 Finns have already been diagnosed with IBD, and on top of that every year the number of new diagnosed patients increases with over 2000. The etiology of IBD has been researched, but information that could be generalized has not been found yet (Bettany & Gardiner 2013). Hereditary factors are common in several diseases and it has been suggested to be also one of the reasons for inflammatory bowel diseases. Individual's habits and surroundings can also be factors of becoming ill with IBD since it has been established that IBD concerns mostly people living in the welfare states. (Crohn ja Colitis ry 2016.) Scientists have not found a single reason for IBD to emerge (Färkkilä 2007) and unfortunately no prevention work can be done.

Diagnosis of a chronic disease such as inflammatory bowel disease can be a shock for the patient and the family. Everyday life may require changes after being diagnosed. The disease can have an impact on physical, social and emotional health. (Bettany & Gardiner 2013; Levnoska, Börjeson, Hjortswang & Frisman 2014.) Relationships, work, free time and studies can suffer due to the symptoms of IBD and new coping methods are needed to restore the daily life (Levnoska et al. 2014).

Chronic disease can lower and complicate the ability or possibility to practice a profession one desires or is currently in. In previous studies, there has not been shown remarkable limitations with people who have either CU or CD when choosing a profession. It goes without saying that inflammatory bowel diseases might complicate working life due to symptoms of the disease such as tiredness or increased need of void the bowels. One might also miss work because of follow-up visits and possible medication treatment at the hospital. In worst case of scenario, disease symptoms might force a patient to change profession, quit or retire. Nevertheless, most of the patients can continue working in the same way as before the disease burst. (Färkkilä 2007.)

Colitis ulcerosa and Crohn's disease are both classified as inflammatory bowel diseases. However, they are two separate diseases with various symptoms, different treatment options, complications and location in the gastrointestinal tract. For this reason, it is vital to view both diseases separately. It is also important not to confuse IBD and Irritable bowel syndrome

(IBS) with each other. IBS is a functional disease of the intestine, less severe and the symptoms are easier to control with simple actions (Crohn ja Colitis ry 2016).

2.1 Colitis ulcerosa

In Colitis ulcerosa the normal function of the bowels is disturbed. It is a chronic disease and incurable. Mucosa of the colon and rectum are damaged causing the symptoms of CU, which usually appear gradually (Tiusanen 2016; Crohn ja Colitis ry 2016). Colitis ulcerosa can emerge at any age but typical patient groups of CU are young adults and fifty to sixty year olds (Mustajoki 2016). As in many diseases the reason that cause CU is yet unknown. However, it is found in many studies that genetics prone individual to fall ill with Colitis ulcerosa. (Sipponen 2015.) Remarkable is that evidence presents that smoking eases the symptoms of Colitis ulcerosa and smokers suffer from CU less than non-smokers. Colitis ulcerosa is more common of the two inflammatory bowel diseases. (Mäkinen 2012.)

There are three forms of Colitis ulcerosa; mild, moderate and severe (Sipponen 2015). Symptoms are usually similar with all of the diagnosed patients. Continuous bloody diarrhea and stomachache that relieves after defecating are main alerts of CU (Crohn ja Colitis ry 2016; Tiusanen 2016). Consequently, without early diagnosis weight loss, fatigue, and anemia due to loss of blood with feces are common effects (Crohn ja Colitis ry 2016; Mustajoki 2016). Depending on the stage and the location of the disease in the colon the severity of the symptoms vary. These can emerge irregularly, meaning changes between symptom-free life and periods of when symptoms exist. Other symptoms include changes in eyes or pain in joints. (Crohn ja Colitis ry 2016.)

Diagnosis is confirmed with samples taken from the bowels and examined by microscopy (Mustajoki 2016). Based on the results the patient receives the information of the stage of the disease and its location in the bowels (Tiusanen 2016). Different blood samples are also taken to get wider picture of the disease (Mustajoki 2016).

After diagnosis is confirmed, best treatment methods will be considered next. Naturally the features of the disease create treatment bases. Medications are preferred and most used treatment method (Mustajoki 2016). Commonly given medications are 5-ASA, cytostatic and biological medicines, which are prescribed depending on the disease's characters (Crohn ja Colitis ry 2016). Pharmacological treatment will be modified and increased if needed for example with cortisone and antibiotics (Mustajoki 2016). The medication treatment alone is not always enough. In that case surgery is required and part of the bowels is removed. Less than half of the CU patients have to be operated. Unnecessary operations are avoided since either ileostomy or stoma would have to be made. The decision is made carefully and usually when

there is no other possibility. (Bettany & Gardiner 2013.) Treatment of colitis ulcerosa is life-long (Mustajoki 2016).

2.2 Crohn's disease

The other inflammatory bowel disease is Crohn's disease, which presents some of the same features as Colitis ulcerosa. The disease is not as common as Colitis ulcerosa, yet almost 500 people in Finland are diagnosed yearly. Most of them are young adults and school-aged children. (Tarnanen, Jussila & Vuorio 2011.) As in CU the exact pathogens of CD are unknown, but hereditary factors play an important role (Käypä hoito 2011). Small intestine and colon are the most common places where Crohn's disease is found. It can also affect the whole area of gastrointestinal tract, which causes abnormal function of the bowels. (Crohn ja Colitis ry 2016; Käypä hoito 2011.) Mortality numbers of Crohn's disease patients seem to be slightly increased compared to healthy individuals (Käypä hoito 2011).

Symptoms of CD are similar with CU, which makes diagnosis occasionally challenging. Symptoms including diarrhea, weight loss, pain in stomach and fever can exist and change with duration and density. Other symptoms such as nausea, bloody diarrhea or constipation are important information if the diagnosis is unclear. Occasionally symptoms can be seen in external appearance, meaning changes in eyes or skin. (Crohn ja Colitis ry 2016.) More than two thirds of Crohn's disease patients have changes between active symptoms and remission phases (Tarnanen et al. 2011).

If Crohn's disease is suspected several examinations are being done. Endoscopy, biopsy specimen and feces samples are basic procedures that are performed. More examinations such as gastroscopy, capsule filming and Magnetic Resonance Imaging (MRI) or computer tomography (CT) can be considered if needed. (Käypä hoito 2011.) Control meetings are arranged regularly based on patient's condition but usually between couple of months or yearly (Tarnanen et al. 2011).

There is no cure for Crohn's disease and treatment lines focus on improving quality of life (Käypä hoito 2011). High percentage of CD patients will at some point need surgery and operations might need to be done more than once (Bettany & Gardiner 2013). However, surgery will not be considered until it is seen as the last option. Medications are the primary treatment method and their response for individual is tested in follow-up visits. (Käypä hoito 2011.) Pharmacological therapy is chosen based on Crohn's disease characters and most used ones are cytostatic, 5-ASA and biological medicines (Crohn ja Colitis ry 2016). Corticosteroids are prescribed for patients who do not get enough results from generally used medications. That usually considers about half of the CD patients. (Käypä hoito 2011.) Especially patients

with Crohn's disease are usually guided and encouraged to meet a nutritional therapist due to possible deficiencies that can emerge. Tobacco and other similar products will increase the possibility for Crohn's disease to activate again. Due to this smokers' benefit would be to quit smoking. (Tiusanen 2016.)

3 Nursing guidance in inflammatory bowel diseases

Nursing guidance consists of giving information, counseling and teaching patients. Educational, emotional and concrete support forms are three center concepts of what the nursing guidance should include. (Kyngäs & Hentinen 2009.) Nowadays' holistic care aims to emphasize individualized patient guidance. Younge & Norton (2007) summarize this well: "A patient wants to be seen as an individual, not as a diagnosis". The health care professionals should always try to give guidance that meets the needs of the patient in question. Children's, young adults', adults' and elderly's needs for guidance differ from each other and should be acknowledged in all nursing guidance. However, patients regardless of their age are often shocked and confused after a diagnosis of a disease. A chronic disease such as IBD is lifelong and enough time should be reserved for patient guidance. Unfortunately, there is rarely enough time for it (Kääriäinen & Kyngäs 2006). Due to the great number of IBD-patients in all age groups there is now an increasing need for more specialized and individualized care and guidance. Therefore, hiring and educating competent IBD-personnel is required.

Guidance is affected by the time, place and the situation where the it takes place. They should all be as neutral as possible for the patient to be able to receive information. Calm, informative and open conversation is aimed. The trust and the relationship between the nurse and the patient also impacts how the patient receives information. (Kääriäinen & Kyngäs 2006.)

Outpatient clinics and health care centers provide the primary care and guidance for IBD-patients (Nykopp 2015). However, nowadays units often lack enough personnel. The responsibility of the care and monitoring is handed primarily to the patient himself. The role of the IBD-nurses' is emphasized, too. IBD-nurses' practice aims to reach patients as well as possible, which enables easy and quick access for services. This is highlighted especially during the active phase of the disease. (Färkkilä 2014.)

Multi-professional team of IBD-patients can consist of several experts such as specialist doctors, nurses, a psychologist, a dietitian and a physiotherapist (Amplo & Nelson 2009). The best results are received when the health care professionals of different fields are participated in the care of IBD-patients and their cooperation is functional (Younge & Norton 2007). Younge & Norton (2007) state that instructions given by doctors may be limited with easing the disease symptoms. They suggest that doctors look for best treatment methods rather than focusing on the overall picture of a patient living with a chronic disease. However, doctors' medical expertise is vital in IBD-patients' care and should not be belittled. Nurses often approach the patients from different angle and they might be more competent to understand the psychological and social aspects the disease causes (Younge & Norton 2007).

Multidisciplinary team's expertise is crucial in the nursing guidance of IBD-patients due to the disease's diversity. Most of the patients are not familiar with the disease before it bursts, which highlights the importance of informative and versatile patient education. The symptoms of IBD can have a major impact for patient's normal life (Bettany & Gardiner 2013) and mental and physical health can be jeopardized. Therefore, the patient should be able to meet different members of the health care team in every stage of the disease. It is especially needed when the disease is diagnosed. (Amplo & Nelson 2009.) Patients suffering from IBD should also have the contact information, preferably a phone number of the treating unit. This benefits the patients since they can directly call to the unit to receive advice about issues related to their disease. (Younge & Norton 2007.)

Stoma nurses can be an essential part of the multidisciplinary team since they are specialized for caring IBD-patients with permanent or temporary stoma. They give instructions not only about washing up and cleaning up the stoma but also about eating and exercising. After a stoma surgery many adjustments may be required since the stoma is located in the stomach area. Thus, it is visible to eyes and can have a major impact on an IBD-patient's psychological and physical health. (Sirviö 2014.)

According to Todorovic (2012) depression is common among IBD-patients and psychological support is often needed. Due to the nature of the inflammatory bowel diseases the quality of life can weaken, notably during symptomatic phase. The IBD-symptoms such as increased need of voiding the bowels can restrict the possibility to work or study normally (Crohn ja Colitis ry 2016). Running errands or enjoying a former hobby might suddenly feel difficult or impossible. Therefore, one of the most important themes in nursing guidance of IBD-patients is to give enough support and instructions for them to have the same possibilities to enjoy life as anyone else would have (Amplo & Nelson 2009).

Peer support groups are made for people suffering from the same disease. These can be one of the most important support providers for a chronically ill patient in addition to the support received from family and friends. Negative feelings can arise after a diagnosis of a lifelong disease has been made. Talking with one's peers and hearing experiences of someone who suffers from the same disease might ease the feelings of loneliness and being isolated. (Younge & Norton 2007.) In Finland Crohn and Colitis association offers peer support for IBD-patients amongst other organizations and support groups.

Guidance related to nutrition and diet is challenging in Crohn's disease and Colitis ulcerosa. Majority of the IBD-patients feel that food affects to their disease's aggressiveness. They try to control symptoms by dropping out some foods and substituting them with something else. Previous studies have expressed the difficulty to give coherent guidance for IBD-patients in

nutritional matters. Food that eases the symptoms of some can do the exact opposite to others. Thus, the same directions for every IBD-patient cannot be given. However, the patients should be aware that by avoiding specific foods there can emerge severe nutritional deficiencies and they should be guided about it from behalf of health care professionals. The deficiencies include vitamin deficiencies, which can increase the risk of osteoporosis among other things. The patients would benefit from more of a tailored diet plan, focusing on an individual's eating habits to control the symptoms. (Vidarsdottir, Johannsdottir, Thorsdottir, Bjornnsson & Ramel 2016.)

Dietitians are mainly responsible of the nutritional guidance that IBD-patients receive although doctors and nurses should be able to provide the same information for patients. Nutritional therapists are often seen as vital even though not many patients are guided to meet one. (Prince, Moosa, Lomer, Reidlinger and Whelan 2015.) In a study made by Prince et al. (2015) it was discovered that only a minority of the patients had met a dietitian concerning their weight loss or gain that IBD had caused.

The most reliable and successful guidance includes oral and written instructions. This stands also especially for guidance related to medication treatment. In order for the IBD-patient to be able to fully commit to the pharmacological therapy, relevant information of the implementation of the medication treatment should be given. The health care team should explain clearly the expected results of pharmacotherapy but also what sort of side effects can arise. (Anttila, Knuutila, Leiviskä, Palmgren & Ylinen 2014.)

Cooperation between the patient and the health care team is necessary for successful care to take place. Active participation of the patient strengthens the client-nurse relationship and motivates the patient to follow instructions. Although changes in health often compromise the feel of security, higher satisfaction occurs when patients participate in their own care. (Kääriäinen & Kyngäs 2006.) It is essential that the individual is comfortable with the decisions made about one's own care and has enough information to participate in planning the care (Todorovic 2012).

All IBD-patients should have a nursing care plan. However, according to the results of IBD2020 study the majority of the Finns suffering from IBD do not have a proper care plan made (Nykopp 2015). The care plan requires careful planning and needs to be changed according to the symptoms present. Effective and functional nursing guidance increases the IBD-patients' confidence and the capability to manage the disease at home (Todorovic 2012). When patients take responsibility of their own care overcrowding of phone calls and unnecessary visits at the hospitals can be avoided. Thus, it gives the health care team more time to plan and execute the care plans individually.

4 Physical activity in relation to inflammatory bowel diseases

It is important to know the differences between physical activity, physical fitness and physical exercise before physical activity and its relation to IBD can be further discussed. Physical activity means the voluntary moving of skeletal muscles. A movement requires energy. Thus, the physical activity intensifies the body's metabolic rate to be greater than the resting energy expenditure. (Bouchard, Blair & Haskell 2012, 12; Käypä hoito 2015.) Physical activity can be divided into many sub-categories based on the intensity of the activity. It can be performed at very light, light, moderate, hard, very hard or maximal intensity, which can be measured with the heart rate, for example. (Bouchard et al. 2012, 13.)

Physical fitness is "the ability to perform muscular work satisfactorily" (Bourchard et al. 2012, 14) and is often measured by health or performance (Käypä hoito 2015). It is linked with the "ability to perform physical work" (Bourchard et al. 2012, 19). Physical exercise means such physical activity that usually has a goal. It is performed for specific reasons often as a hobby. (Käypä hoito 2015.) Exercise is planned and it aims to achieve or sustain physical fitness (Bourchard et al. 2012, 19). Athletes are people who do a lot of exercise to have great physical fitness as they compete in sports that require technique, strength and endurance. Therefore, they often perform with hard to maximal intensity and consume much more energy than average people.

Physical activity affects the body in many positive ways. When physical activity is increased it often results in better physical fitness, which in turn results in better health. (Lynn 2006.) Health promoting factors can be seen in cardiovascular, muscular, motor, morphological and metabolic components. Physical activity improves heart and lung functions, power, strength, endurance, coordination, flexibility, and glucose tolerance to give some examples of each component. (Bourchard et al. 2012, 16) However, these only represent a small number of all the positive effects of regular physical activity on health.

The recommendation for adults in the age of 18—64 is to exercise endurance at least 150 minutes with moderate intensity or 75 minutes of hard intensity weekly. In addition to that moderate-intensity power and strength training should be done twice a week. If physical activity exceeds this minimum amount it can start having disease preventive and curative effects. For example elevated blood pressure and diabetes mellitus type two are diseases that can be prevented and treated by increasing physical activity. (Käypä hoito 2016.) Physical activity has also been linked with reduced risk to fall ill with breast and colon cancers (Bourchard et al. 2012, 232) and patients with IBD are at higher risk to fall ill with the latter (Mäkinen 2012).

The relation between IBD and physical activity has not yet been broadly studied. It can be stated that people suffering from IBD most likely benefit from physical activity. Exercise reduces stress and results in better mental health. That is beneficial for IBD-patients, as elevated stress levels are linked with relapse of the diseases. Weight management will help in avoiding comorbidities and exercise may have positive effects on the degree of inflammation. However, the disease symptoms can greatly affect the IBD-patients' possibilities to be physically active. (DeFilippis et al. 2015.)

In a study of 227 IBD-patients over 40% of research participants answered that the disease has restricted their capability to exercise. However, most of them were still able to be physically active. Symptoms that were reported to affect exercising were fatigue, joint pain, weakness, urgency, bowel incontinence and abdominal pain. Also embarrassment was mention as a reason and was linked with having a stoma or looking for a bathroom. (DeFilippis et al. 2015.) In another study it was reported that patients with Crohn's disease have more trouble with exercising than Colitis ulcerosa patients and it was mostly linked with disease activity and illness perception (Van der Have et al. 2015).

A research by Zaltman, Braulio, Outeiral, Nunes and Castro (2013) suggests that women suffering from Colitis ulcerosa are more likely to suffer from mobility limitations when compared with a control group. The women with IBD had reduced strength in lower limbs and had reported to be less active physically than the matched control group. They conclude that it could be useful for women with Colitis ulcerosa and pre-clinical stage of disability to have regular controls of weight and an individual exercise and diet plan.

Health care professionals should be able to guide IBD-patients about physical activity in all stages of their disease, but for now it seems that the patients are getting poor guidance on the subject. The patients or the healthcare professionals do not appear to know what is the proper amount of exercise when suffering from IBD. (Nathan, Norton, Czuber-Dochan & Forbes 2013.)

5 Purpose and aim of the study and the research question

The purpose of this thesis was to describe Finnish athletes' experiences of IBD-nursing guidance.

The aim of the thesis was to discover new information to develop IBD-nursing guidance in Finland.

The research question was: "What kind of experiences of IBD-nursing guidance do Finnish athletes have?"

6 Qualitative study

The research question of a thesis determines whether quantitative or qualitative research method should be used. If the question asks how much or how often, the research method used is quantitative. It aims to study large amounts objectively and presents results as numbers (Vilkka 2007). On the contrary, qualitative research method aims to describe and understand phenomena through findings (Pitkäranta 2014, 7; Brinkmann 2013, 50). The amount of research participants in a qualitative study is much lower than in a quantitative study, because of the nature of describing phenomena instead of aiming for statistical generalizations (Brinkmann 2013, 144). Therefore, qualitative research method was a natural choice for this thesis, as the purpose was to describe Finnish athletes' experiences of IBD-nursing guidance.

In a qualitative research the researcher will have an effect on the study process by choosing the concepts and how data is gathered, analyzed and reported. It is important for the researcher to acknowledge one's influence on the research process and try to stay on the background. The voice of the research participants should be at the center of a qualitative study. (Hirsjärvi & Hurme 2008, 18.)

Qualitative research method has two central methods for collecting data, interview and observation (Kankkunen & Vehviläinen-Julkunen 2013, 121). Qualitative interview is typically used when researching people's experiences, language and communication, and society and culture (Brinkmann 2013, 47). Observation is used to study similar matters as interview and is often suitable, if nothing or only little is known about the topic (Kankkunen & Vehviläinen-Julkunen 2013, 122). In this thesis the data was gathered by using interview as the method. Brinkmann (2013, 47) is of the opinion that qualitative interviews "lend themselves most naturally to the study of individual lived experience." Athletes who suffer from inflammatory bowel disease and have gone through diagnosis and treatment were interviewed.

Qualitatively gathered information is usually analyzed with content analysis. It is used to describe and analyze the data at the same time. Content analysis is well suitable for nursing science and was used for this thesis. Content analysis can be done with inductive or deductive approach. Inductive analysis is based on the data where as deductive analysis is based on theory or theoretical concepts. The analyzing method used for this thesis was inductive content analysis, because it should be used when there is not much previous knowledge on the subject, like in this case. (Kankkunen & Vehviläinen-Julkunen 2013, 163-167.)

Inductive content analysis proceeds step by step and the research question guides the whole process. After collecting the data it has to be first simplified, then categorized and finally

abstracted. The goal is that in the end the data would be compacted and could be described on a prevalent level. Usually the analysis results with some sort of models, charts or conceptual system. (Kankkunen & Vehviläinen-Julkunen 2013, 166-167.) No previous research, which would have studied athletes' experiences on IBD-related nursing guidance, was found. Therefore, the analyzing had to start with the data that was collected during the interviews (Hirsjärvi & Hurme 2008, 150). Inductive content analysis is a rather flexible method, because there is no strict formula on how to proceed with it (Kankkunen & Vehviläinen-Julkunen 2013, 167). Thus, the researcher's influence is emphasized during the analyzing process.

6.1 Study participants

In this thesis athletes were chosen to be interviewed about IBD-nursing guidance. They can be called informants, because they represent a particular group and have special knowledge on sports (Hirsjärvi & Hurme. 2008, 46). It was hoped that they could give insight to overall IBD-nursing guidance and tell how Finnish healthcare professionals address physical activity. Here athletes are defined as people, who compete in sports that require physical strength and endurance. Competing at least on a national level when diagnosed with either Colitis ulcerosa or Crohn's disease was a precondition to be interviewed. Competitive and professional athletes were addressed, both present and retired.

Athletes whom the writers of this thesis knew to suffer from an inflammatory bowel disease contacted via circle of acquaintances and an IBD-related organization. When getting in touch with these people, some of them were also asked if they knew other athletes suffering from IBD, who could possibly want to share their experiences as well. The method is called snowball sampling (Pitkäranta 2014, 98). It means that one or few key men gather more people in the study through their influence (Hirsjärvi & Hurme 2008, 59-60). In this study there were two key men, who provided contact information of other athletes.

In a qualitative study the minimum of researched subjects or research participants is one (Pitkäranta 2014, 30). The aim for this study was to interview four to eight athletes to give more extensive findings than by interviewing a single person. Five male athletes were interviewed. Four of them suffer from Colitis ulcerosa and one of them has Crohn's disease. Not one of them had required surgery due to IBD. They represented four different sports, both individual and team sports. All athletes had been competing in national or international level. They had continued with their sports careers despite the diagnosis, with the exception of two taking a short break to recover after it. None of the retired ones said that the disease influenced their decision on quitting their sport.

To be able to perform a qualitative research it is crucial to inspire confidence in the research participants (Pitkäranta 2014, 14). This is why the study, contacting the informants and recordings of the interviews were planned carefully. The participants were assured about the confidentiality and good ethical conduct of the researchers in a covering letter (see Appendix 2). It was emphasized that the analysis would be done in such way that the interviewees could not be identifiable and that the informants could quit at any time of the process. Thus, the participation was completely voluntary. These matters were repeated in the beginning of each interview. The participants were also offered the possibility to receive the hyperlink to the published thesis via email.

Acquaintances of one of the writers of the thesis were first contacted to get the contact information of possible informants. Email-addresses and phone numbers were received. The possible informants were first either emailed or text messaged by briefly presenting the thesis' topic and asking if they would tentatively be willing to take part in the interview. Most agreed to the request immediately and the covering letter was sent to all contacts as an email attachment. Later as some interviews had already been done, the snowball sampling started working and the informants were contacted with the covering letter email directly. All informants that were contacted had to be of age to be able to self give the consent to participate in the study. The consent was asked to be given by answering to the covering letter emails of the thesis authors. The time and place for the interviews were discussed and agreed at the same time. Six athletes gave their consent of whom one dropped out before the interview time was arranged.

6.2 Qualitative interview

Interview was used as the method in this thesis. Qualitative interviews can be structured, semi-structured or unstructured (Hirsjärvi & Hurme 2008, 43-48). A semi-structured strategy was chosen for this study. Peculiar to this form of interview is that some elements are predetermined but not all of them. In a semi-structured interview each research participant will be asked the same open-ended questions but the order of asking the questions may differ. The informants are able to answer the questions as they will, thus the answers are not specified. (Hirsjärvi & Hurme 2008, 47.) Semi-structured interview was narrowed down to what Hirsjärvi and Hurme (2008, 47) name "theme interview" (translated from Finnish word teemahaastattelu). In a theme interview instead of asking the same specific questions from each interviewee, the goal is to cover themes that have been set in advantage on the grounds of the study's theory (Hirsjärvi & Hurme 2008, 48). The defined theme or themes aim to get answers to the research question (Pitkäranta 2014, 92-93). In this study it was: ”What kind of experiences of IBD-nursing guidance do Finnish athletes have?”

The themes of the interviews in this thesis were background information, experiences of IBD-related nursing guidance, physical activity and IBD, and proposals for improvement. There were also subthemes under each main theme. Although it is not expedient in a theme interview to prepare questions word for word, some opening phrases concerning the themes had been written down as an aid for the interviewers. Essential to this type of interview is that it emphasizes what the interviewees tell (Hirsjärvi & Hurme 2008, 48). As the interviewees were able to talk freely, sometimes they covered all the subthemes simply by being asked to tell about the main theme.

Already when planning the interviews it was important to take into account the language and possible misunderstandings that might occur during the interviews. Hirsjärvi and Hurme (2008, 48-50) mention the communicative competence in relation to qualitative interview. It means that via communicative competence both parties of the interview have a common language and are able to communicate using it in the interview situation. That was the case in these interviews and it lead to understanding of each other. However, even when speaking the same language connotations still needed to be taken into consideration (Hirsjärvi & Hurme 2008, 53). They are secondary meanings to words that vary among people for example in different dialects and thus can lead to wrong interpretations despite the common language. To avoid connotations, the interviewers asked the informants to specify if anything seemed unclear.

Before the actual interview situations took place the writers of the thesis tested the intended themes so that one acted as the interviewer and the other as the interviewee. This way improvements were made to opening phrases and subthemes were revised. It also helped the interviewers to prepare for the upcoming interview situations. In addition the interviewers studied a book on theme interview (Hirsjärvi & Hurme 2008). Practical advice was gotten from it on how to act and what to say when first contacting the possible participants and during the actual interviews. The interviewers' main goal was to inspire confidence in the informants and to get them to relax to get as good answers as possible.

Deciding on the interview settings, time, structure, length, questions and way of recording were also part of the planning (Hirsjärvi & Hurme 2008, 73-75). Because of interviewing athletes, it had to be taken into account that they might be at camp or competing abroad for long times. They might live and practice in Finland but could live far away from the capital area. Therefore videophone call was also proposed as an alternative for the traditional face-to-face interview.

The interview times were agreed with each participant individually and the informants were able to suggest convenient times for them. In all cases video call was seen as the best option

to arrange the interview. It made it easy to conduct the interviews with a short notice as well. The advantage of videocalls was that they were possible to do even when the interview participants were physically far from the interviewers.

In an interview setting video calls are better than regular phone calls in many ways. The interviewers were able to see the facial expressions and gestures of the informants just like when interviewing face-to-face. Therefore, they were able to evaluate the body language in relation to what the informant was saying (Hirsjärvi & Hurme 2008, 74). When the informant is seen by the interviewer, he or she is less likely to do other things simultaneously. The interviewers also considered that the informants might appreciate that they can see who they have been in contact with. Talking about one's disease might be a sensitive matter and it was considered to be easier to form trust if the informants could see where the interviewers were and that there was no one else there to see or hear the conversation. The interview points chosen by the informants and the interviewers were peaceful and light, as they should be (Hirsjärvi & Hurme 2008, 73-74). Only minor interruptions occurred during one interview due to pets making noise. The informants were located at their homes or offices and the interviewers interviewed from home.

Technical difficulties were reckoned with already before any interviews were done. The interviewers were prepared to use three applications that offer free video calls. This gave the opportunity to switch to another application if the calls did not go through at all, which happened in one case. The two applications that ended up to be used were WhatsApp and Skype. Regardless of the options, problems with the camera occurred in two interviews. In one interview the interviews could not see the informant at all and another interview the picture froze and the informant could not see the interviewers. One of the informants did not want to put the camera on.

The interviews were recorded with two tape recorders, just in case one of them would not work. The recordings were loaded on both thesis writers' computers for transcribing them. The interviews were transcribed to be able to reread them many times and to make notes on the documents. Transcribing the data was done by the authors of this thesis by listening to each interview recording and typing them down on separate files by using Microsoft Word. The files were named "Interview 1" "Interview 2" and so on. The transcribing was done after each individual interview. It took time from approximately two to five hours depending on the style of speaking and the length of the answers of the informants. Everything that the informants said was transcribed and most of what the interviewers said, but not all. The themes were the same for each interview participant so there was no need to transcribe opening phrases of main themes. However, all clarifying and specifying questions that were interview-

specific were written down to be able to evaluate their influence on the findings. After the thesis was written, the recordings were erased.

The interviews took place in January and February 2017 and they were all approximately 30 minutes long. Both of the writers of this thesis were present in every interview. This benefitted the interviewers since both could ask specifying questions, which lead to more extensive answers.

6.3 Analysis

The inductive content analysis began by becoming familiar with the data. Familiarizing with it started already when listening to and transcribing the recordings. Then the interviews were reread several times to find similarities and differences in what the informants had said. (Hirsjärvi & Hurme 2008, 143) Next, all answers that were about the experiences of IBD-related guidance, or the lack of it, were underlined. Also proposals of improvements were perceived at this point. Then, the rather long phrases of the informants were simplified. The simplifications were written on the interview files following the actual answer of the informant. Simplifications were typed with bold type to distinguish between what the informants had originally said and what the writers had typed. They were short sentences that resembled headings. The idea was to try to keep them as descriptive as possible with the least amount of words. Two examples of simplifications are illustrated in Figure 1.

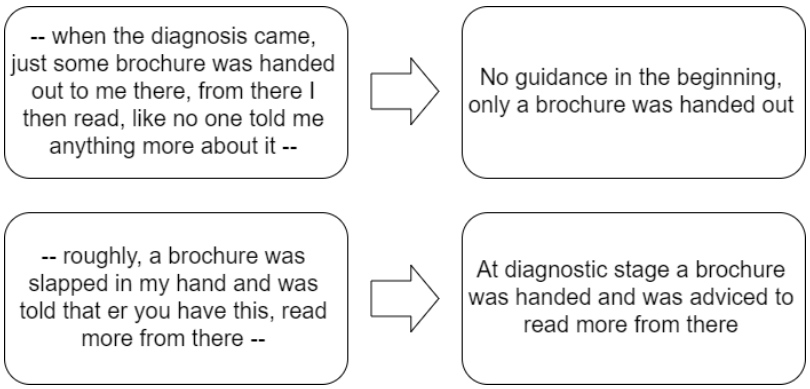

Figure 1: Simplifications of quotations

The simplifications from all interviews were gathered on a separate coding file (Elo & Kyngäs 2007). Each simplification got a code in front of it. The numbers of the codes indicated, which interview the simplification was initially from and the letters indicated where it stands in the coding sheet. In Figure 2 the examples are from the second and third interview on the very top of the coding sheet with the letters “A” and “B”.

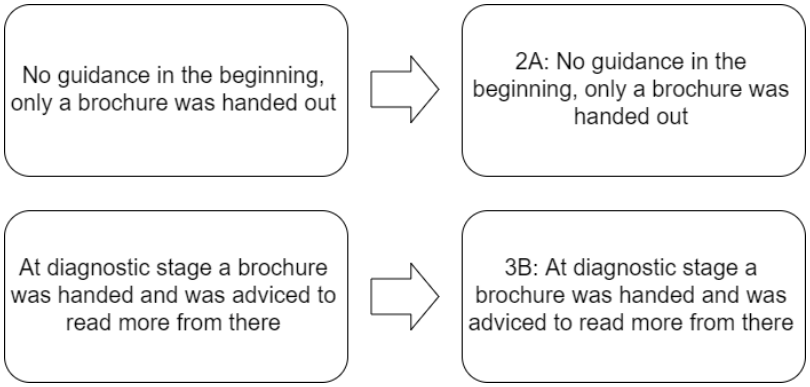

Figure 2: Coding of simplifications

The simplifications talking about the same themes or otherwise similar to one another were grouped one below another with the same color font on the coding sheet. For example all simplifications that described medication guidance were colored with brown and nutritional guidance with green font. This loose combining of simplifications helped when the actual categorizing started, which was the next step of the inductive content analysis (Kankkunen & Vehviläinen-Julkunen 2013, 167). The simplifications did not always belong just to one theme and the loose grouping was only used to help in finding the similar comments as the categorizing into subcategories began. Sub-categories were formed if there were two or more simplifications stating the same thing. The codes in front of the simplifications made sure that not two simplifications from one and the same interview would create a sub-category. The common factor of the simplifications became the name of the sub-category. Altogether twenty-nine sub-categories were formed describing the experiences about guidance received. The sub-categories were named after the simplifications and typed on a separate file. An example of formation of a sub-category is shown in Figure 3.

Then, the names of the sub-categories were written down on pieces of paper that were placed on a big cardboard. The thesis writers started thinking which sub-categories describe similar kind of experiences and could form a generic category. It was easy to move the pieces of paper on the cardboard and it enabled trying different kinds of groupings. When the two thesis writers agreed on all of the groups, the generic categories were named and written down on a separate computer file also. At this point names of categories were written down in Finnish and English. Eleven generic categories were formed as shown in Figure 4. Two sub-categories remained on sub-category level as they did not seem to belong to any of the groups formed.

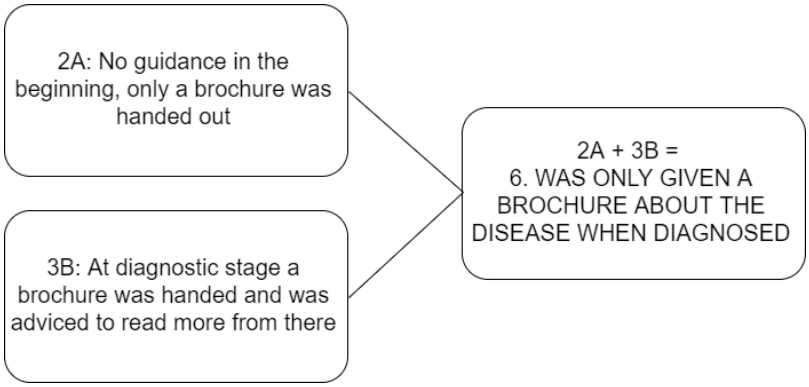

Figure 3: Simplifications with codes forming a sub-category

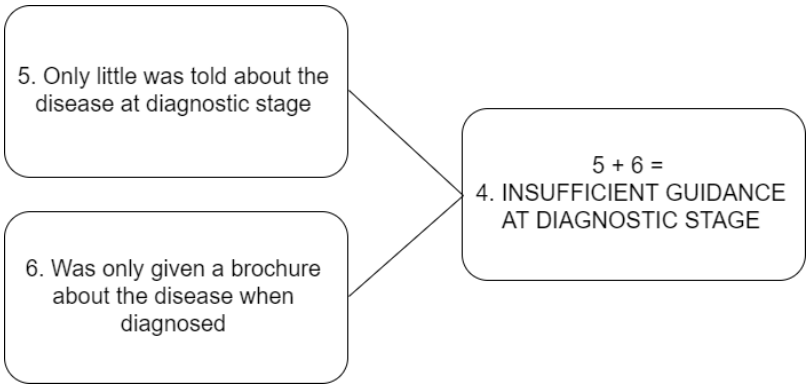

Figure 4: Two sub-categories forming a generic category

As an end result four main categories were formed from the eleven generic categories to generalize the experiences of the athletes. That stage is shown in Figure 5. Three categories remained on the generic level. The main categories were named in English at that time. The aim was to give all the categories names that would specifically describe the experiences as creatively and accurately as possible. Thus, the purpose of the study and the research question were kept in mind the whole time.

The forming of generic and main categories took several hours and different viewpoints and ideas were discussed. Kankkunen and Vehviläinen-Julkunen (2013, 167) claim that the inductive content analysis is challenging because it gives so much freedom that the researcher must think about the grounds for the forming of categories. They also argue that too simple findings often indicate that the process is not finished yet. During this analysis some subcategories were eliminated in the analyzing process as they were seen as irrelevant to the study question and not all sub or generic categories could be included into a higher category.

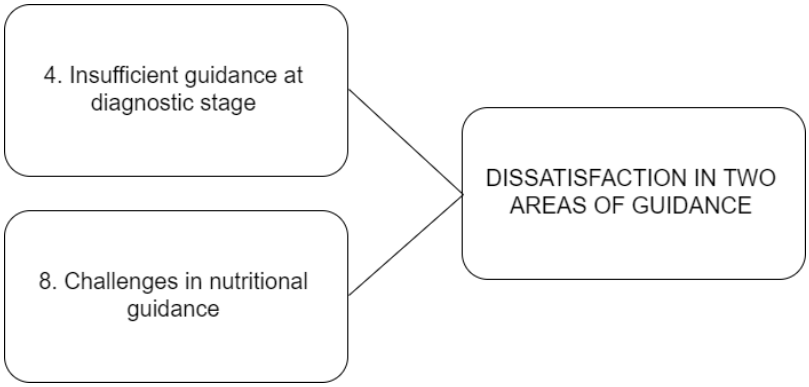

Figure 5: Two generic categories forming a main category

Translations from Finnish to English were made during the process by first translating the generic, then the main and lastly the sub-categories. An example of a sub-category translation is shown in Figure 6. Other translations shown in the figures and quotations were made afterwards when reporting the analyzing process, findings and discussion.

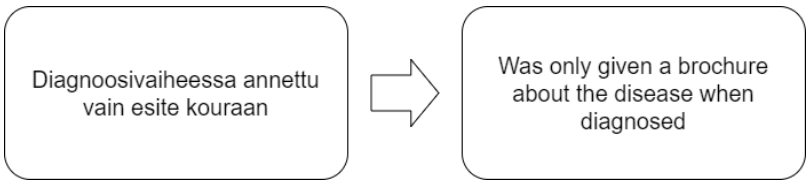

Figure 6: Translation from Finnish to English

7 Findings

The thesis' purpose was to describe Finnish athletes' experiences of IBD-related nursing guidance. As previously mentioned, the data was collected by interviewing five male athletes. Interviews included four pre-determined themes and several sub-themes. Interviews were analyzed using inductive content analysis.

Based on all the interviews four main categories were produced: "Contentment with overall guidance", "Importance of information received from elsewhere", "Dissatisfaction in two areas of guidance" and "Lack of regarding sports as a factor". Discussion of the content of these categories is presented in this section. Figure 7 was created to illustrate the categorization. The findings also include direct quotations of what the informants have said in the interviews in Finnish and they have been translated into English. The quotations have been used to describe the findings.

7.1 Contentment with overall guidance

Three generic categories, "Successful medication guidance", "Health care professionals' sufficient knowledge" and "Communication possibilities with health care professionals" created the first main category, which resulted from the biggest amount of sub-categories. Figure 7 demonstrates the process of eight sub-categories forming the generic categories and in the end, the main category.

Experiences related to medication guidance in general were positive and the guidance fulfilled the needs of the informants. Especially the athletes who had gotten biological medications were pleased with the guidance that was given related to them. The implementation of all pharmacological therapy was explained clearly.

Informant 2: "Mä oon nyt näitä biologisia (lääkkeitä) saanu -- niin sit kyllä siitä tosi hyvät niinku ohjeistukset ja opastukset tuli niinku lääkäriltä ja hoitajilta. -- Siinäki sai jonku esitteen toki ja sitte ihan suullisesti, että molempia--."

"I have now gotten these biologicals (medications) -- so yes like very good instructions and guidance was received from the doctors and nurses then. -- There I received some brochure of course and then also just orally, so both--."

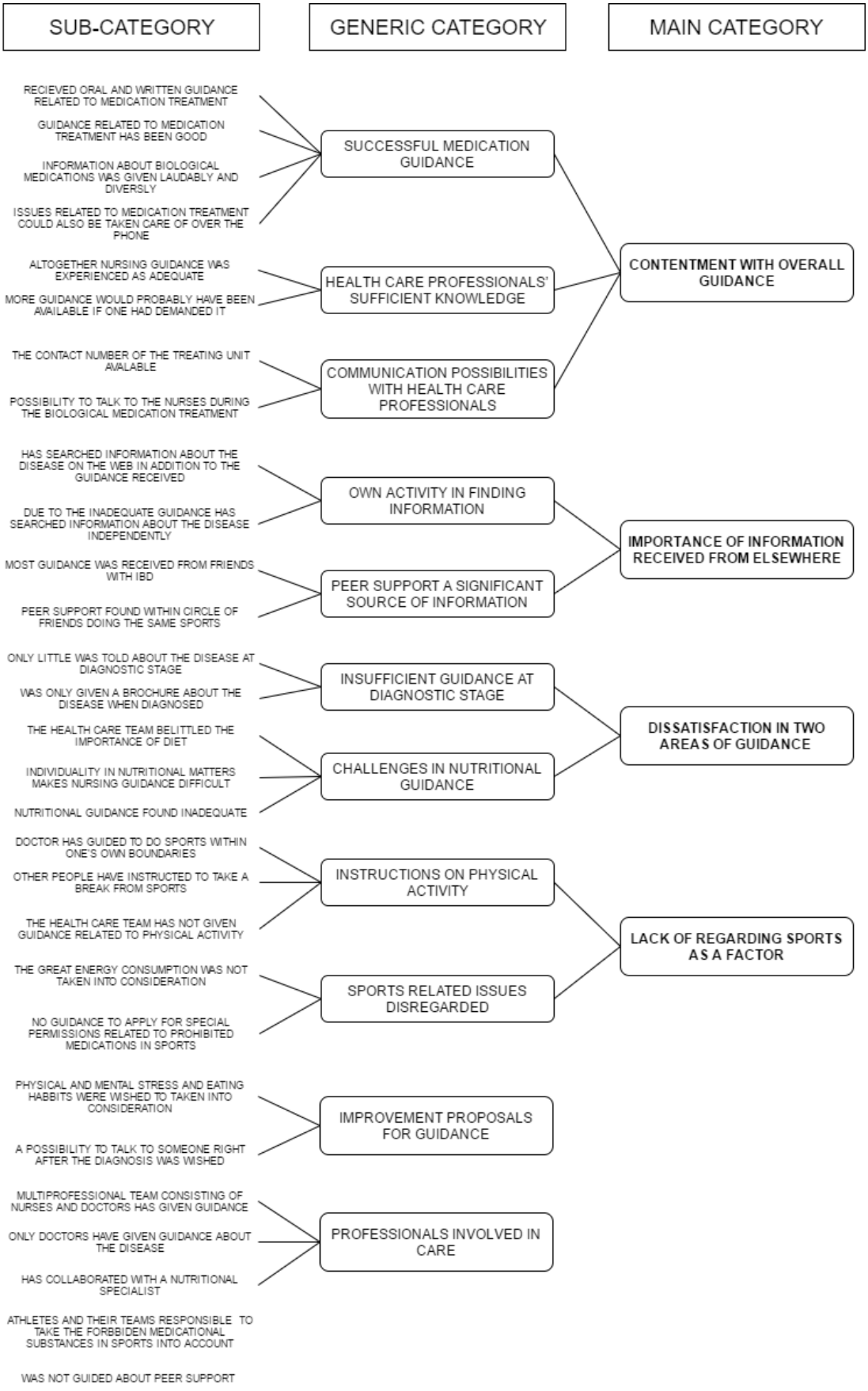

Figure 7: All categories

Instructions came from the doctors and nurses and were given orally and in writing. The unit where the disease was diagnosed and the medications that has been prescribed affected who gave the guidance about medications to the patient. Different possibilities to contact the treating unit concerning the medications were also mentioned by the athletes, which enabled quick consultation also from a long distance. The informants said they had the phone number of the treating unit where they could call directly and receive instructions on IBD-related issues. The informants agreed that the health care team could have provided more information in addition to what was given, if one had required it.

All in all the guidance that had been received was described as sufficient even if the athletes had not received much information. They experienced that health care professionals gave the most important information and then they themselves were capable to find out the rest.

7.2 Importance of information received from elsewhere

Own activity in finding information and peer support as a significant source of information were experienced as important. The main category was derived from these two generic categories that were based on four sub-categories. The categorization has been described in Figure 7.

Two main reasons arose for the need to search for more information independently: own interest concerning the disease and lack of guidance received from the health care professionals. Information was searched related to medications and IBD-symptoms among other things. For example more information about medication was read due to own interest about the subject even though the health care professionals had given versatile instructions on it and the informant had been satisfied with the given guidance.

In case the athletes had experienced that the guidance received from the health care professionals was not adequate they found other ways to fill the gaps. No or little guidance was given related to diet thus the athletes had searched a lot of information about it independently.

Informant 3: ”No oikeestaan suurimmaks osaks mä oon ite niinku ruvennu selvittää sitä niin kun et mitä kaikkee tähän kuuluu--.”

“Well actually for the most part I have begun to find out about it myself that what sort of things belong to this--.”

Interviewed athletes emphasized the importance of support and guidance from their friends. Most athletes knew someone within their own sport who also suffered from an inflammatory

bowel disease and they were often seen as the best source of information. They could share advice they themselves had found working well. None of the informants questioned the reliability of friends as a source of information, and they desired more information about peer support organizations from behalf of health care professionals.

Informant 3: ”--yhen kaverin kanssa joka myös urheili niinku isolla tasolla ja sillä oli kans myös niinku jonkin sortin saman tyyppinen tauti. Niin tota sen kans juttelin asiasta.”

“--with one of my friend who also did sports in top level and had also some sort of similar disease. So I talked with him about the issue.”

Informant 4: ”--mul oli yks kaveri kel on sama sairaus ni se autto mua aika paljon -- ja se oli itseasias kans -- [saman lajin urheilija].”

“--I had one friend who has the same disease so he has helped me a lot -- and actually he used to be a -- [same sport athlete].”

7.3 Dissatisfaction in two areas of guidance

Third main category was derived from generics categories “Insufficient guidance at diagnostic stage” and “Challenges in nutritional guidance” which were formed based on five subcategories. Figure 7 illustrates the development of these sub-, generic and main categories.

At diagnostic stage the interviewed athletes experienced that not enough information and guidance was given about the disease. The situation was not handled properly either concerning the fact that one had just been diagnosed with an incurable chronic disease. Time and resources for guidance were seen inadequate and it was one sided. It was hoped that someone had told more about the disease right after the diagnosis had been made.

Informant 2: ”--kun se diagnoosi tuli, niin sitä annettiin vaan joku esite kouraan siinä, siitä sitten luettiin, että ei sitä kukaan sen enempää mitään kertonu, -- oli vähän ihmeissään, että mitähän tää niinku tarkottaa. Et ois sen paremminki voinu hoitaa.”

“*--when the diagnosis came just some brochure was handed out to me there, from there I then read, like no one told be anything more about it, -- I was a bit confused what this like means. It could have been handled better.”*

Informant 5: ”Sillon vaan kerrottiin, että tää on Colitis ulcerosa eli haavainen paksusuolentulehdus ja se johtuu siitä -- mutta aika vähän siitä niinku keskusteltiin. Että sanottiin vaan,

et sun oma keho hyökkää jostain syystä sun suolistoa vastaan ja sielt vuotaa verta ja se pitää sit se tulehdus saada lakkaan lääkkeillä. Et siinä se aikalailla oli."

"Then it was just told that this is Colitis ulcerosa also known as ulcerated colitis and it is caused by -- but like quite little was discussed about it. It was just told that your own body attacks against your intestine for some reason and it bleeds blood and the inflammation has to be stopped with medications. That was pretty much all that there was to it."

Guidance related to diet was longed for. The informants themselves felt nutrition is crucial in controlling the symptoms of IBD but guidance related to it was lacking. However, they acknowledged that what works for someone might not work for everyone, which complicates the ability to give coherent guidance about diet for IBD-patients.

Informant 2: "No siis kyllä käytännössä siihen ravitsemukseen liittyen niin tuntuu, että aika monen lääkärin mielestä ei sillä oo niinku mitään merkitystä --. --Ja yleensäkki varmaan niinku ei sitä ehkä huomioida tarpeeks--."

"Well practically, concerning the nutrition it feels that quite many doctors think that it does not matter at all--. --And in general maybe like it is probably not taken into account enough."

Informant 3: "--sitä niinku jotenki vähäteltiin sitä niinku ruokavalion merkitystä."

"--it was somehow kind of belittled the like meaning of diet."

7.4 Lack of regarding sports as a factor

Fourth category was comprised of five sub-categories and these compounded to two generic categories, "Instructions on physical activity" and "Sports related issues disregarded". The names of the sub-categories are represented in Figure 7.

With athletes sports play a huge role in their lives. Yet the guidance they had received related to physical activity was quite limited and given on a more general level. Some of the informants reported they had not received any guidance related to physical activity even though the health care professionals knew they were competitive or professional athletes. The information related to take a break from sports or lower the intensity of it came from the doctors, athlete's circle of acquaintances or a nutritional specialist, but mostly from the latter two.

Informant 1: ”No ei oo isosti oikeestaan ollu semmosta -- et jos tuntuu et ne oireet niinku pahenee sen myötä että tekee [urheilee] paljon ni sit tietenki pitää aina siit keskustella lääkärin kanssa--. Hyvin vähän sanotaanko näin.”

“Well nothing major has been -- that if it feels like the symptoms get like worse due to doing [exercising] a lot then of course it has to be discussed with a doctor--. Very little lets say so.”

Informant 4: ”--ravintovalmentaja sano et älä reenaa nyt, et annetaan sen parantuu ni reenaa sit sen jälkee.”

”--nutritional specialist said not to work out now that let’s let it get cured and so workout after that.”

Neither the enormous energy consumption of the athletes nor the changes in bowel’s functions depending on the sport’s stress were taken into account. It was also found out that the health care professionals are not aware of the special aspects of guiding athletes with IBD such as applying special permissions from World Anti-Doping Agency.

Informant 5: ”-- jos sä oot [oma laji] ni kuinka paljon sitä treeniä oikeesti on ja paljonko sitä ruokaa tarvii. -- En ole lääkäri mut veikkaisin et se ei oo kaikkein parasta, et jos sul on tulehtunu paksusuoli ja sä syöt vaikka 10 000 kaloria päivässä. Mut mut siihen ei niinku puututtu mitenkään et ois sanottu että treenaa nyt vähä vähemmän, jotta se sun suoles voi parantua siitä, vaan se [lääkäri] oli vaan et anto lääkkeet niin kaikki menee hyvi.”

”-- if you are [own sport] then how much exercise there actually is and how much food one needs. I am not a doctor, but I would guess that if you have an infected large intestine and you eat, for example 10 000 calories a day, that is not the best thing to do. But but they did not interfere with it at all that it would have been said, practice less so that your intestine can heal from it, but it [the doctor] was like that [he] gave the medications so everything goes well.”

Informant 2: ”No eipä sitä neuvottu [hakemaan erityislupia], että kyllä mä sen ite tiesin ja olin ottanu selvää, että tiesin, että tämmöset pitää.”

”Well it was not told [to apply for special permissions] that I knew it myself and had found out about it that I knew that these have to be.”

8 Discussion

The purpose of this thesis was to describe Finnish athletes' experiences of IBD-nursing guidance and to answer to the research question: "What kind of experiences of IBD-related nursing guidance do Finnish athletes have?" Five Finnish male athletes told about their experiences of IBD-related nursing guidance in individual theme interviews. The interviews were transcribed and analyzed by using the inductive content analysis. The transcribed data was altogether 44 pages long and twenty-nine sub-categories, eleven generic and four main categories were formed as a result to describe those experiences. The purpose of the study was fulfilled and answers were received to the research question. It has also been agreed that the published thesis will be send to Helsinki, Kuopio and Turku University Hospitals' gastroenterology outpatient clinics to help in improving the nursing guidance of IBD-patients. Thus, the thesis succeeded to reach the aim to develop IBD-nursing guidance.

During the interviews it came out that the informants had received rather little if any guidance particularly from nurses and so the findings describe more the overall experiences of IBD-related guidance received. When examining the findings it has to been taken into consideration that some athletes had gotten their diagnosis many years ago and the guidance might have improved since. Some had also been in remission for quite a long time already and did not have experiences about guidance within the recent years. However, there were also informants with fairly new diagnosis and similarities in experiences of guidance were reported. The degree of difficulty of the disease affected how often the informants had been communicating with the health care staff. Thus, those with moderate or difficult degree of disease had encountered nurses and doctors more often and had had more guidance situations compared to the ones with a long remission. Despite differences some conclusions can be drawn from the findings.

8.1 Discussion of the findings

The findings disclose that overall guidance was evaluated as adequate although the athletes were not content with the guidance received at diagnostic stage. Following factors emerged as the athletes described their dissatisfaction in guidance in the early-stage. The time for guidance and discussion considering the fact that one had just been diagnosed with a lifelong disease was described as too short. Kääriäinen and Kyngäs (2006) have also brought out that there is often too little time reserved for nursing guidance. In some cases guidance was lacking completely and the responsibility to familiarize with the disease was shifted to the patient alone. It was found out, too, that no less than four out of five informants had been diagnosed with IBD in a private clinic. The fact that most athletes had bad experiences of how diagnosing was handled could also be affected by the lack of nursing guidance in the private

clinics where they were treated at that time. Wong et al. (2012) have also acknowledged the lack of guidance at diagnostic stage in their study. They conclude that only a small percentage of IBD-patients were content with the amount of information that was shared with them when diagnosed.

In two cases gastroenterologists were the only professionals involved in the care and guidance, apart from examinations, as the care was sought from the private sector only. Eventually three out of five athletes were treated in public hospitals and there all had encounters with nurses also. The informants said that nurses had more time to talk to the patients than doctors did. Therefore, we suggest that all patients would be directed to meet a nurse specialized in inflammatory bowel diseases right after the diagnosis, including the private clinics. The nurse would be able to discuss with time what the diagnosis actually means, how it might impact the patient's life and what sort of things need to be taken into consideration from then on. A model similar to this is already used in the Hospital District of Helsinki and Uusimaa gastroenterology outpatient clinic and would most likely benefit patients elsewhere, too.

The findings of this study showed that the doctors and nurses had given medication guidance diversely. Oral and written guidance was given. The athletes had received enough information about side-effects and the implementation of the medication treatment. Thus, the medication guidance was experienced as good. These findings are coherent with what is suggested of how IBD-patients' guidance related to medication treatment should be done (Anttila et al. 2014).

Talking about guidance in general some of the athletes felt that more guidance and instructions could have been available if one had demanded it. The reasons behind why the athletes did not ask specifying information could be due to several factors. The too short meetings with the health care professionals could be linked with why the athletes did not demand more information even though they felt it was available. One of the informants even stated that after couple of bad experiences with the health care professionals it was better to find out about the disease elsewhere. Thus, the health care team was not able to form a confidential relationship with the patient, which is required for successful guidance to take place (Kääriäinen & Kyngäs 2006).

The findings show that peer support was viewed as an important if not the most important source of information and support. The significance of peer support has also been acknowledged in previous studies, where patients suffering from IBD have evaluated peer support as more important than the support from family members, friends or professionals (McMaster, Aguinaldo & Parekh 2012). However, not all athletes had been referred to peer support, alt-

hough it was viewed essential in coping with the disease. Not only the nurses giving guidance to the patients but also doctors, who are the ones breaking the news about the lifelong disease should keep that in mind. They should encourage patients to tap peer support right from the beginning, when they are most out of countenance as it is.

All informants reported that they had been searching information about the disease in addition to or instead of the received guidance from the health care professionals. They said that if one is active it is possible to find a lot of information on the Internet. One mentioned also the downside of the possibility of finding information of poor quality. Thus, it would be desirable that the patients were reminded about source criticism and would be told about reliable webpages like Terveyskirjasto and Crohn and Colitis association. Wong et al. (2012) also acknowledge that it would be beneficial to invest in good quality information websites and brochures.

Diet's relation to IBD had interested the informants and they had searched information about it themselves. Most wondered the lack of nutritional guidance and strong opinions were expressed about the health care staff not paying enough attention to the diet as a possible help in controlling the disease symptoms. The athletes also felt that health care professionals had been belittling nutritional matters. Other studies show that IBD-patients perceive diet as significant. They believe it influences the course of their disease (Holt, Strauss & Moore 2016) and they would want more guidance on it (Wong et al. 2012). The findings of this thesis did not make an exception.

Holt et al. (2016) have found out in a study of 928 patients and 136 clinicians that only 26% of patients said that they had been given guidance on nutrition, although 98% of the gastroenterologists taking part in the study claimed that they had been guiding their patients. During the interviews it came out that some doctors indeed had mentioned that it might help to avoid some foods or spices but the instructions did not seem precise. The problem of giving clear guidance seems to be the lack of scientific evidence on nutritional matters and IBD and the need for research has been acknowledged in the field of study (McMaster et al. 2012; Richman & Rhodes 2013). It would be important for the health care professionals to follow the latest findings on diet and to have consistent instructions for the patients for example Current Care Guidelines with most recent information. Dieticians should be included in the multi-professional team, because unlike nurses and doctors, they are specialists in nutrition and have experience of nutritional guidance. The informants reported that they had not even been suggested to meet with one even when loosing a lot of weight, but some had done it on their own initiative.

Although holistic care is emphasized in nursing today, the findings reveal that the best guidance is given on medication and individuality is not taken into account enough. Not even competitive or top athletes have been receiving information regarding IBD and physical activity or if they have it has been remote. This finding is consistent with earlier study results on guidance of physical activity in relation to IBD (Nathan et al. 2013). In the care it was not reckoned with that the athletes might exercise up to thirteen times a week and consume a much greater deal of energy than regular people.

It would be important that in the future the caregivers would take the continuous stress situation of the athletes' bodies into consideration when they are working on trying to calm the inflammation. The health care professionals should evaluate together with the athlete and his team (e.g. coaches, parents, carers and possible sport physicians) the need to adjust the physical activity if there are acute symptoms of the disease. The age of the athlete and the competence of the team surrounding him are likely to influence the capability to make informed decisions on the intensity of physical activity when suffering from acute symptoms. That is why timely nursing guidance and information about physical activity and IBD is needed.

All in all it can be stated based on the findings of this study that individuality in nursing guidance of IBD-patients is still at a developing stage even though its importance is emphasized in patient care. The study found out the positive experiences of IBD-related nursing guidance of the athletes that participated in this study, and issues that need further improvements. The findings show that for the IBD-nursing guidance to reach all patients suffering from IBD organizing the care must yet be worked on, especially in the private sector.

Several recommendations for further studies could be proposed. As this study is quite small, a study with larger amount of informants would give a wider picture of the topic and lead to more reliable findings. Female gender should also be represented and the differences in guidance between the private and public sectors could also be further studied. Since the number of patients suffering from inflammatory bowel diseases has increased rapidly in other countries as well, the experiences of athletes could be studied internationally to find out the present quality of guidance worldwide. The effects of IBD for performing sports and the relation between diet and inflammatory bowel disease's activity need further studying also in order to be able to base the guidance on scientific knowledge.

8.2 Ethical considerations

“The ethicality of a study is the core of all scientific activity” (Kankkunen & Vehviläinen-Julkunen 2013, 211). Therefore, ethical considerations of this study had to start already when deciding on the thesis' topic and when defining the purpose of the thesis. The writers fulfilled the ethical demand of intellectual interest by choosing to study experiences that had not seemingly been studied before. Thus, this thesis has produced new information concerning the nursing profession. (Kankkunen & Vehviläinen-Julkunen 2013, 211.)

As this thesis studies people's experiences it was important to take into account how the rights of the participants of the study could be ensured throughout the process. This includes the planning of the interviews, contacting the research participants, analyzing the data, authenticating it and reporting the findings (Hirsjärvi & Hurme 2008, 20). It had to be made sure that the autonomy of the informants was respected, they gave an informed consent about participating in this study and their anonymity was and will be protected (Kankkunen & Vehviläinen-Julkunen 2013, 218-221).

A covering letter was produced with the thesis plan. It was directed to the possible interviewees to inform them about the thesis, assure them confidentiality, guarantee their anonymity and to promise good ethical manners as carrying out the study. The assumed time and effort the thesis causes to the informants were mentioned in the letter as well. Those are all key ethical principles in addition to the consent of interviewees and privacy when talking about a study concerning people (Hirsjärvi & Hurme 2008, 20). The informants had the opportunity to give their consent via email or pass. All informants approached had to be of age to be able to self give the consent for the interview. In the beginning of the interviews they were reminded that it is voluntary and they are entitled to quit at any time. None of the interviewees with whom interview times had been arranged withdrew from the study. The informants had the possibility to ask questions concerning the thesis before and after the interview.

Each interview was made as an individual interview to protect the privacy of the informants. The interviews were recorded to get more precise view of the interview and its details, which the interviewers might have missed during the interview (Hirsjärvi & Hurme 2008, 92). The recordings could be played again several times and thus helped the interviewers to write and analyze the interviews. The writers of the thesis guaranteed in the covering letter and in the beginning of each interview that the material would be used only for the purpose of executing this thesis and will then be destroyed. When writing the recordings of the interviews to Microsoft Word no names of the informants were used, and the files were named as “Interview 1, 2, 3, 4 and 5”. The names of the informants are not shown in the thesis and the analysis generalizes the findings in such manner that informants cannot be recognized. Also quo-

tations have been modified so that information that could reveal the informants' sport has been left out. The names of the acquaintances or the IBD-related organization contacted were not mentioned in the text either to protect the anonymity of the informants.

The access to the raw data was protected carefully by keeping it behind locks and passwords. Also messages and contact information were deleted as soon as they became irrelevant to the study for example if a person contacted did not want to be interviewed. Only the emails where the informants gave their consent were kept, however, after the thesis has been published those emails will be deleted as well. The writers have promised during the interviews to send the link to the published thesis to those informants who requested it. After fulfilling that promise the remaining contact information will be deleted.

The thesis writers' responsibilities and duties of good ethics had to be taken into account during the process. The writers have kept their word to the informants and fulfilled the demand of integrity by telling the truth at all times. They have not been guilty of plagiarism, lying or falsification of data. The writers have also had collegial respect to one another and worked towards a common goal without diminishing each other's work or talent. (Kankkunen & Vehviläinen-Julkunen 2013, 211-212.) No third parties were involved in the process and the writers are independent from any sponsors.

This thesis process has followed Laurea guidelines that are set by Laurea University of Applied Sciences to help students to write their thesis in a reliable and ethical manner. This thesis' topic was first approved at a thesis meeting. Then a topic analysis was written and approved by two lecturers. After getting the permission to continue with the chosen topic, a thesis plan was written and introduced to a tutor lecturer and fellow students. When the plan was presented, the ethicality of the study was evaluated and discussed with the others and some improvements were made. Last, the study was carried out and the final thesis was written.

8.3 Trustworthiness of the thesis

In order for the readers of this thesis to be able to evaluate the trustworthiness of the findings, the writers have provided enough information about the whole process from the beginning to the end. Explaining the study design and showing all the steps of categorization of the data in as much detail as possible have done this. The idea has been to show the link between the interviews and the findings. Interview quotes have been used to demonstrate what the raw data was like and to add to the reliability of the thesis. (Elo & Kyngäs 2007.) They also give interesting and wider descriptions to the categories. The figures show how simplifications of the informants' answers were made and then grouped into subcategories. The forming of broader categories has been explained and demonstrated with figures also. The data has

been coded with such accuracy that the writers were able to check and see if the name of the main category is in line with the simplifications and interview answers. Throughout the categorization the research question has been on display to avoid forming irrelevant categories.

The study and its findings are based on honesty from both parties involved, the writers of the thesis and the informants that were interviewed. The informants have voluntarily taken part in the study and know that the findings could help other people in a situation similar to theirs. For that reason it is expected that they have been telling the truth while talking about the interview themes. As the theme is related to their disease, the sensitivity of the matter might have influenced the answers to be constricted. As for the thesis writers, they have committed to follow ethical guidelines in conducting this study. This has obliged them to tell the truth in every part of the thesis.

The gender and the number of the informants can be considered as limitations of this study. All five informants that were interviewed were men, although the thesis writers tried to have the female gender represented too. Thus, the thesis only presents experiences from one gender's perspective. It has to be taken into account, too, that only one of the informants suffered from Crohn's disease and therefore the findings represent more the experiences of Colitis ulcerosa patients. The study is also rather small and the findings cannot be generalized. Nevertheless, the study could be repeated even though some of the contact information of the informants were gotten from acquaintances of one of the writers of the thesis.

Both interviewers and interviewees had expectations for the interview and earlier experiences of interviews affected the interview situation (Hirsjärvi & Hurme 2008, 95). Inexperience of the writers of this thesis could have affected the process of interviewing the informants and writing the thesis since it was the interviewers' first time conducting a study. Interviewers noticed situations where some of the questions might have been too leading toward a specific direction, which might have affected the informant to give an answer that was not as open as it was hoped to be. Some answers have similarities with each other and these answers might not have come up without asking the informants about specific sub-themes or to specify their answer. Some of the interviewees' experiences are from several years back and might not represent the nursing guidance given nowadays. The informants were from different parts of Finland thus the findings present experiences of IBD-related nursing guidance from several health care districts.

Problems with the technology could have influenced the interpretation of the answers in two interviews. As the interviewers were not able to see the informants, they could not evaluate their body language at all in regard to what they were saying. In another interview the informant was not able to see the interviewers, which could have influenced his capability to

trust the interviewers. However, in this particular case the informant was an acquaintance to one of the interviewers and the trusting relationship had been established already beforehand. Not seeing the interviewers most likely had no influence in the openness of the answers.

Translations from Finnish to English took place when analyzing the data and were written as detailed and clearly as possible based on the original answer that was received. The thesis writers who are native Finns but have had English as their school language for the past three and a half years have made the translations. It must be taken into account that someone else could have phrased the translations otherwise. However, two people have done them together and striven for equivalents as good as possible. There is one example of how the name of a sub-category was translated in the analysis section and other examples in forms of quotations in the findings and discussion section.

One of the strengths of this thesis is that the writers have been working as a pair. As each person views the data from their own perspective, two can challenge each other's views (Elo & Kyngäs 2007). A tutor lecturer has also been available during the process to support in planning the thesis and in coding and categorizing data. However, it has to be noted that someone else could have formed categories and named them differently.

An article of the thesis will be published in the Finnish Crohn and Colitis association's member magazine and on their Internet pages. It has also been agreed that the published thesis will be send to Helsinki, Kuopio and Turku University Hospitals' gastroenterology outpatient clinics to help in improving the nursing guidance of IBD-patients.

Writing of this thesis has taken approximately one year. The topic was chosen, presented and approved in the spring of 2016. Information retrieval about the subject was carried out at that time. After that the work was put on hold. The thesis plan was written in about a month in the end of the year of 2016. It covered the theory of the thesis, the study design, analyzing method and ethical considerations with reliability. Only after a tutor lecturer carefully evaluated the plan and improvements had been made, the writers were allowed to send the covering letters to the informants. They were sent in January of 2017. Interviews were conducted in January and February of 2017. The thesis' final version was written, presented and opposed February 2017.

All references in the thesis plan and in this final thesis have been marked according to Laurea guidelines and only references considered reliable have been used. The references used have mostly been less than ten years old with the exception of couple references.

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Figures

Appendices

Appendix 1: Interview themes in English and in Finnish

Interview themes in English and in Finnish

Background information

Experiences of IBD-related nursing guidance

Physical activity and IBD

Proposals for improvement of nursing guidance

Perustiedot

Kokemukset IBD:hen liittyvästä potilasohjauksesta

Fyysinen aktiivisuus ja IBD

Parannusehdotukset hoidonohjaukseen

Appendix 2: Covering letter

LAUREA AMMATTIKORKEAKOULU / Yhdessä enemmän /

Saatekirje opinnäytetyön haastattelupyyntöön

18.1.2017

Arvoisa urheilija,

Olemme tänä keväänä valmistuvia sairaanhoitajaopiskelijoita Laurea Ammattikorkeakoulun englanninkielisestä koulutusohjelmasta. Opintoihimme kuuluu opinnäytetyön tekeminen ja aiheemme on tulehduksellista suolistosairautta sairastavien urheilijoiden kokemukset hoidonohjauksesta.

Aihe on hyvin ajankohtainen, sillä suolistosairaudet ovat yleistyneet Suomessa nopeasti. Omasta kilpaurheilutaustastamme johtuen olemme kiinnostuneita nimenomaan urheilijoiden kokemuksista. Omakohtainen kokemuksenne hoidonohjauksesta on ensiarvoisen tärkeä. Opinnäytetyön tulokset voivat auttaa kehittämään hoidonohjausta laadukkaammaksi ja yksilöllisemmäksi.

Opinnäytetyö kirjoitetaan englannin kielellä otsikolla "Athletes with inflammatory bowel diseases and their experiences of IBD-nursing guidance". Tutkimuksen aineisto kerätään haastattelemalla urheilijoita. Haastattelukieli on suomi. Haastattelut toteutetaan yksilöhaastatteluina erikseen sovitussa paikassa teidän aikataulunne puitteissa. Mahdollisuuksien mukaan pyrimme sopimaan haastattelut tammi-helmikuulle. Haastattelu voidaan tehdä myös videopuheluna. Aikaa haastattelulle olisi hyvä varata noin 30 minuuttia.

Pyydämme kunnioittavasti teitä osallistumaan opinnäytetyömme aiheeseen liittyvään haastatteluun. Haastatteluun osallistuminen perustuu vapaaehtoisuuteen ja sen voi jättää kesken missä vaiheessa hyvänsä. Haastattelu nauhoitetaan ja nauhoitetta käytetään ainoastaan opinnäytetyöhön. Haastattelun materiaali ja nauhoitteet säilytetään siten, että vain opinnäytetyön tekijöillä on mahdollisuus nähdä tai kuunnella niitä. Saatu materiaali hävitetään ja haastateltavien yhteystiedot poistetaan opinnäytetyön valmistumisen jälkeen. Haastateltavien henkilöllisyys on ainoastaan opinnäytetyön kirjoittajien tiedossa, eikä heitä voi tunnistaa lopullisesta opinnäytetyöstä. Sitoudumme vaitiolovelvollisuuteen ja noudattamaan hyviä tutkimuseettisiä toimintatapoja opinnäytettä toteuttaessamme. Ammattikorkeakoulujen opinnäytetyöt julkaistaan Theseus.fi -tietokannassa ja halutessanne voimme lähettää teille linkin valmiiseen opinnäytetyöhömme.

Toivomme, että vastauksenne haastattelupyyntöön on myönteinen. Suostumuksenne haastatteluun voitte antaa vastaamalla tähän sähköpostiin. Olemme tämän jälkeen teihin yhteydessä sähköpostitse sopiaksemme haastattelupaikasta ja -ajankohdasta. Jos teillä on kysyttävää opinnäytetyöstämme, vastaamme mielellämme.

Kunnioittavasti,

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