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Patient Counselling about Stress Associated with Irritable Bowel Syndrome - A Qualitative Study Based on Patient Experiences

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ABSTRACT

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The purpose of this study was to gather information from patients that have been diagnosed with irritable bowel syndrome and to investigate if they had experienced that stress affects their symptoms. In addition, it was studied if patients had received patient counselling about stress and what stress related topics the respondents would like to include in the counselling hereafter. The aim of this study was to gain information that could be utilized in the development of irritable bowel syndrome patient counselling.

The present study was conducted by utilizing a qualitative research method. The data was collected through Webropol with a questionnaire that included one close-ended and three open-ended questions. A link to the survey was published in Facebook in a peer support group called FODMAP Suomi which is targeted for irritable bowel syndrome patients. Altogether 29 respondents participated in this study. The data was analyzed by utilizing inductive content analysis.

The findings of the study were divided into three subheadings according to the three open-ended survey questions. These subheadings were The effect of stress on IBS symptoms, Experiences of patient counselling including stress and Patients' suggestions for IBS stress counselling. According to the findings, most participants had experienced that stress affects their IBS symptoms. Most common effects were aggravation of diarrhea, bloating, flatulence and abdominal pain. The results also presented that nearly all respondents had not received any type of patient counselling. A minor number of the participants were briefly mentioned about stress during their counselling. On the other hand, two partakers had been satisfied with the patient counselling they had gained during their treatment. A significant number of the respondents came up with different suggestions for future stress counselling topics for IBS patients. Counselling about the possible effect of stress and stress management methods were most often proposed in the survey answers. Precise methods were also suggested including yoga, using of natural products and guidance to relaxation courses.

Key words
Irritable bowel syndrome, IBS, patient counselling, stress, symptoms

CONCEPT DEFINITIONS

FODMAP	Fermentable, Oligo-, Di-, Mono-saccharides and Polyols
GI tract	Gastro intestinal tract
IBS	Irritable bowel syndrome

ABSTRACT
CONCEPT DEFINITIONS
CONTENTS

1 INTRODUCTION

Irritable bowel syndrome, also known as IBS, is a common functional disturbance of the intestines. The condition does not cause any structural changes to the bowel but the altered function can induce a variety of symptoms. These symptoms include bloating and flatulence, diarrhea or constipation and abdominal pain. At the moment, approximately more than half of the western population have functional problems with their bowel, yet 70 % of them will not seek medical attention. In Finland, at least one out of ten people suffer from this condition and it is twice more common among women than men. The syndrome is not dangerous and no severe illnesses are associated to it. However, studies have shown that IBS patients more often suffer from for example fibromyalgia, sleep disturbances, depression and stress.

For the time being, studies have not discovered an exact cause for the syndrome. However, health care professionals have found evidence that defective communication between the brain and intestines could be one of the causes. This faulty communication can induce unusual muscle spasms leading to cramping pain, diarrhea or constipation and bloating. It has also been studied that IBS patients are more prone to have abnormally sensitive intestines. In addition, scientists have been able to identify several different factors that can cause these symptoms such as eating certain types of carbohydrates, hormonal changes, some medicines, an infection in the gastrointestinal tract and genetics. Furthermore, the symptoms can be affected by psychological factors due to bowel's reaction to tenseness and trepidation. The most common psychological predisposing factors are anxiety, depression and stress.

Based on several different studies, researchers have found out that stress can be associated with the onset of IBS. In addition, chronic stress has reportedly worsened the symptoms after the onset and throughout the whole lifespan of the syndrome. Therefore it is important that diagnosed people would receive patient counselling about stress and how to manage with it. Lowering the level of stress could possibly alleviate the symptoms. Alternative treatment methods such as progressive muscle relaxation or yoga could be beneficial. Moreover, ensuring the amount of good night sleep and exercise have shown positive effects with the management of symptoms. However, IBS patient counselling is at the moment focusing more on dietary treatment methods. No tailored counselling material about stress is available for the use of this patient group even though the condition is very common in the population.

Lack of proper counselling has provoked patients to create many peer support groups in social media. For example, a quick search in Facebook can find four general IBS peer groups and 13 IBS diet related support groups. In general discussion, patients have been unsatisfied with their treatment and especially counselling. Based on these observations, the purpose of this study was to gather information from diagnosed IBS patients and to investigate if they had experienced that stress affects their symptoms. The author also studied if patients had received patient counselling about stress and what stress related topics participants would like to include in the counselling in future. The aim was to gain information for the development of IBS patient counselling.

2 THEORETICAL FRAMEWORK

2.1 Definition and symptoms of irritable bowel syndrome

Irritable bowel syndrome, which will be further on referred as IBS, is a functional impediment of the intestines. The syndrome does not cause any structural changes in the gastrointestinal tract which is also known as GI tract. IBS can include various different symptoms but the most distinctive ones are stomach swelling due to gas production in the GI tract and pain which can be located in different parts of the abdomen. Generally the function of the bowel has changed; some people defecate many times per day and the stool can vary between soft, diarrhea like stool and constipation. The feces can also be small and slimy. Many patients feel that the bowel does not empty properly when they are defecating but abdominal pain can decrease after a toilet visit. Most patients experience that abdominal swelling and flatulence worsen towards the evening time. (Mustajoki 2015.)

According to Talley (2013), even though IBS does not cause obvious structural changes to the intestines, the symptoms remain very real for the patients. For example the severity of pain can vary between mild and very severe. Pain is also associated with the frequency of bowel movements or with the texture of the stool. However, IBS patients may also experience other types of symptoms which are not linked with their bowels. These so called “extra-bowel symptoms” are tiredness or fatigue, muscle aches, back pain, heartburn and nausea. They are more common with IBS patients when compared to the general population. In addition, migraine headaches and urinary symptoms such as feeling of urgency and increased frequency are also more common with IBS. Until now, the possible explanation for these symptoms could be linked with how IBS patients’ brains are processing pain signals from the body.

The cause of IBS still remains unclear but experts assume that there might be several different problems that may lead to IBS. One of the possible causes might be located in the function of brain-gut signals. There are signals between the brain and the nerves in the intestines and these signals regulate the function of the bowel. If there are problems with these signals, it might lead to IBS symptoms. Another reason could be a faulty motility of the colon. Leisurely motility can result as constipation and too rapid activity of the intestines can lead to diarrhea. Furthermore, researchers have discovered that IBS patients can have extra sensitive nerves

in the bowel, which increases the person's sensitivity to feel pain or discomfort. (National Institute of Diabetes and Digestive and Kidney Diseases 2015.)

The National Institute of Diabetes and Digestive and Kidney Diseases (2015) explains that the cause of IBS might also be due to infections that have occurred in the GI tract. In addition, some scientists are studying a link between IBS and bacterial overgrowth in small intestines. The overgrowth is either an increment in the amount of bacteria or a difference in the type of bacteria living in the small intestines. Bacterial overgrowth may lead to an increment of gas production, diarrhea or even weight loss. Researchers are also studying if IBS has a genetic cause. For the time being, different studies are suggesting that IBS is more frequent with people whose relatives have a background of GI problems. However, it is commonly thought that food sensitivity plays the most important role as a source of IBS symptoms. Foods which have a lot of carbohydrates, fats and spices, are many times reported to provoke GI symptoms regardless of the fact the people do not have actual food allergies.

2.2 Diagnosing IBS

Patient is diagnosed by firstly identifying the distinctive IBS symptoms. These symptoms have usually existed for more than six months and the condition is worsened by stress or other psychological factors. Secondly, other possible diagnoses are excluded by taking laboratory tests which can include lactose and celiac tests, inflammatory markers and etc. The physician usually wants to check the patient's stool sample to see if it contains parasites or blood. Imaging examinations such as lower GI series, and/or colonoscopy investigation can be performed to exclude for example polyps, inflammatory bowel diseases, cancer and other structural causes. However, if the patient is having characteristic IBS symptoms, the diagnosis can be given with 98% accuracy without performing a wide range of examinations. (Voutilainen 2015; National Institute of Diabetes and Digestive and Kidney Diseases 2015.)

According to Voutilainen (2015), the doctor examines the patient and interviews if he or she has experienced symptoms that are representative to IBS. Patient usually suffers from recurrent abdominal pain or other unpleasant abdominal symptoms. IBS can be diagnosed if these symptoms are present and if the patient is also experiencing at least two of the following distinctive symptoms; Symptom is alleviated after bowel movement, the frequency for need of

defecating is either increased or decreased and the consistency of the stool is changed (either loose/diarrhea or constipation). Other possible symptoms that support the IBS diagnosis are for example abnormal effort to defecate (unusual straining to push the stool out, repetitive need for using the toilet and feeling of incomplete emptying of bowel), mucus containing stool, bloating and flatulence. In addition, patient might experience extra-bowel symptoms but not all patients have them and they can still be diagnosed with the impediment (Talley 2013). When the doctor is certain of the diagnosis, the impediment is subdivided to one of the three categories; diarrhea or constipation oriented IBS or hybrid IBS where diarrhea and constipation are both present.

2.3 Dietary and pharmacological treatments

Within the past few years it has been discovered that symptoms like bloating and flatulence are associated with certain insoluble carbohydrates in nutrition. These carbohydrates will pass through the small intestine to the large intestine where intestinal bacterium will use them as their nutrition. This process called fermentation generates plenty of intestinal gas. Eating of these types of carbohydrates can worsen the symptoms with more than 50% of IBS patients. Researchers from Monash University in Australia have designed a diet which is based on avoiding these short-chained insoluble carbohydrates, generally known as FODMAPs (Fermentable, Oligo-, Di-, Mono-saccharides and Polyols). (Voutilainen 2015; Mustajoki 2015.)

Mustajoki (2015) has explained that foods, drinks and other products containing high amounts of FODMAPs that should be firstly avoided by IBS patients are for instance onions, cabbages and beans. In addition, lactose containing products should be excluded from the diet together with “stomach friendly yoghurts” and “fitness drinks” that usually contain inulin, added fibers and fructo-oligosaccharides. Eating of sweets is also problematic since they have xylitol, sorbitol, mannitol and maltitol in them. If IBS symptoms do not become easier by excluding these products from the meal plan, more strict FODMAP diet can be applied. The person can exclude grain products with high amounts of FODMAPs such as wheat, rye and barley. Mushrooms, pears, apples and fruits with “stone heart” such as peaches and nectarines should also be avoided. The list continues with prebiotics, honey, sugar substitutes and caffeine containing drinks.

FODMAP carbohydrates are found in many products but total avoidance is not possible or even required. Most symptoms are alleviated with small dietary changes. Nevertheless, if a person needs to try the strict FODMAP diet, it is advised that they seek help from a dietician so that the safety of using this diet is ensured. Clinical studies have shown that restricting FODMAP diet has alleviated intestinal symptoms in three persons out of four. The diet will not cure the disease since it is usually chronic, but the diet will help people to manage with their symptoms. Tight FODMAP restrictions should not be long lasting and if symptoms are not alleviated after two months, these strict restrictions should be gradually undone. Furthermore, IBS patients' diet has to be individually planned so that they have sufficiently broad and versatile diet to follow. (Laatikainen and Hillilä 2012; Mustajoki 2015.)

Some IBS patient may also benefit from gluten-free diet. A new research which was published in 2016 found a possible explanation for GI symptoms that are caused by eating grain products. The study included 160 participants with 40 people being completely healthy and 40 of them having coeliac disease. The rest 80 participants did not have coeliac disease but they were chosen based on their reported GI symptoms caused by wheat and gluten. The researchers discovered that the GI symptoms were caused by impaired intestinal wall which released microbes and nutrient particles into the blood stream. As a response, the body activated an autoimmune reaction that became apparent as stomach aches, bloating and diarrhea. These 80 participants' immune systems were unable to neutralize the autoimmune reaction unlike the other partakers. In addition, the study showed that if these 80 gluten sensitive participants applied gluten-free diet for six months, their immune system normalized and the damaged cells in the intestinal wall were healed. (Uhde, Ajamian, Caio, De Giorgio, Indart, Green, Verna, Volta & Alaedini 2016.)

According to Talley (2013), people who suffer from IBS could benefit from the usage of added fiber in their diet. Nutritional fibers are carbohydrates that are indissoluble and therefore not absorbed by the body (Aro 2015). The benefit of fibers are multiple. Fiber can increase the bulk of stool and it has been discovered to help with constipation and even diarrhea. Fiber makes stool softer because it draws water from the large intestine to the stool. On the other hand, it may firm up soft or diarrhea like feces. Lastly, it may even decrease the amount of pressure inside the intestine and therefore ease up the possible symptom of pain.

It is important that fiber is added slowly to the diet, since large increases can cause extra formation of gas and bloating. However, getting enough fiber while using the FODMAP diet might turn out to be difficult, since a lot of vegetables, fruits and grain products belong to the list of avoidable foods. If a person is unable to receive enough fiber naturally from their diet, they can use for example soluble linseeds or buy medicinal fiber products from pharmacy such as Vi-Siblin. (Talley 2013; Voutilainen 2015.)

Due to the fact that irritable bowel syndrome is a functional impediment, the effect of pharmacological treatment is limited. The medicinal interventions are used for symptomatic treatment. Patients may benefit from different types of medicines such as anticholinergics to treat muscle spasms of the intestines or tricyclic antidepressants to help decreasing the sensitivity for abdominal pain. Selective serotonin reuptake inhibitors might be used to enhance the quality of life in chronic treatment resistant IBS. Loperamide, rifaximin and probiotics are used to treat diarrhea, especially during vacations and travelling. On the other hand, laxatives can be used for IBS with constipation. However, there are various types of laxatives available that function in different ways. This means that the physician should decide which is appropriate to use between different individuals and their type of IBS. Some studies have also shown that coated peppermint capsules could alleviate IBS symptoms. Furthermore, since many IBS patients also suffer from for instance anxiety or depression, these patients need medical treatment for these conditions and even psychotherapy. (Voutilainen 2015; National Institute of Diabetes and Digestive and Kidney Diseases 2015.)

2.4 Patient counselling

Vehmasaho and Rantovaara (2010) explain that patient education or counselling is provided by health care professionals and it is defined as an active and systematic teaching-learning process which aims to increase the patient's level of knowledge and skills. The teaching also includes adaptation of the learnt material and the new knowledge is usually applied in practice with concrete actions. On the other hand, counselling can be defined as an active and goal-directed action which is actualized between a professional counsellor and the patient who is the expert of his or her own situation. Counselling is individualized for the patient and it includes for example problem solving and providing guidance. This method is interactive and it supports the patient to find his or her own adaptation mechanisms.

The Finnish legislation states that a patient is entitled to receive information of his/her health status as well as the importance of the treatment, different treatment options and their effect. Also other aspects of care that are important in decision making must be explained to the patient. The health care professional has to provide the information in a way that the patient sufficiently understands the content of it. The Finnish legislation creates a basis and obligation for patient counselling situations. (Vehmasaho & Rantovaara 2010.) According to Kääriäinen and Kyngäs (2006), counselling is an essential part of the professional actions of treating staff and an important part of the clients' treatment. When the patient counselling is successful, it has an effect to clients' and to their families' health, to actions that enhance their health and to the national economy. Short treatment periods and partly insufficient resources set challenges to the execution of patient counselling. Providing counselling in challenging situations demands the caring personnel to identify and recognize the need for counselling.

Due to the obligation set by the Finnish legislation, the author was interested to study if IBS patients in Finland have received any counselling about stress related to their condition. At the moment, the researcher was unable to find studies exactly associated with patient counselling, irritable bowel syndrome and stress together.

3 PREVIOUS STUDIES ABOUT STRESS

Endocrinologist Hans Selye medically defined in 1936 that stress is a physiological adaptive response to physiological or physical stressors (threats) to an organism. An acute threat can induce the “fight or flight” respond which prepares the organism to either fight or escape the situation in order to survive. After the stress passes, body will regain the state of homeostasis. However, if the stressor becomes chronic it can exceed the organism’s ability to maintain the “fight or flight” response. This means that the body cannot reach homeostasis anymore and the chronic stress becomes harmful. (Hong-Yan, Chung-Wah, Xu-Dong & Zhao-Xiang 2014.)

According to Mental Health Foundation (2016), “Stress can be defined as the way you feel when you’re under abnormal pressure.” Stress can be induced in all types of situations yet the most typical causes are work, economical issues and relationships with either a companion or relatives. In addition, major life events such as being jobless or divorcing from the spouse, changing one’s residence or losing a loved one can result in stress. Minor stress triggers can include feeling underrated or caring for challenging children. However, there might not be an exact cause for stress.

3.1 The effect of stress to irritable bowel syndrome

Hong-Yan et al. (2014) pointed out that psychological stress is an essential factor for developing irritable bowel syndrome. Both clinical and experimental studies have shown that this syndrome is a combination of irritable bowel and irritable brain. These studies have also discovered that psychological stress in childhood or adulthood has a significant impact on intestinal sensitivity, motility, secretion and permeability. In addition, the basic mechanism behind these changes also correlates with mucosal immune activation, alteration in central nervous system, peripheral neurons and gastrointestinal microbiota.

In addition, various studies have come to the conclusion that disturbance in the bidirectional brain-gut axis could be a significant factor in the pathophysiology of IBS. This disturbance means that there is abnormal function in the enteric, autonomic and/or central nervous systems. Stress can create over activity or underactivity in the brain and production of adrenalin,

in addition to the autonomic nervous system. Over or underactivity can also affect the metabolism and immune system of the body. These changes can alter the cooperation between brain and intestines which can further lead to physiological disturbances in the GI tract. These disturbances are for instance diminish of gastric emptying, increased length in small intestinal motility and increment of colonic motility. Furthermore, stress can also cause intestinal inflammation in the bowel. (Bonaz, Pellissier, Sinniger, Clarencon & Pennequin 2012.)

It has been recognized that approximately 50% of the IBS patient have a co-morbidity with psychiatric disorders. These disorders are for instance depression or anxiety that can include symptoms such as exhaustion, decreased appetite, sleeping problems, panic attacks and trepidation. Researchers have also discovered that there is a strong correlation between the prevalence of psychiatric disorder and the severity of IBS. A research that was published in 2013 revealed that just before the progression from non-IBS patient to an IBS-patient, there was a remarkable increment in the amount of stressors. Also major life traumas such as divorce, disruption of a close relationship or child leaving home, were regularly reported by the participants 38 weeks prior to the onset of IBS symptoms. Moreover, negative early life events such as physical, emotional or sexual abuse, were also found to correlate with the prevalence of irritable bowel syndrome. Due to the strong correlation between IBS and psychiatric disorders, it is suggested that these types of patients should receive more general and collaborative care instead of specialized care, since it might lead to a treatment that only focuses on the physiological aspects. Health care professionals should become more aware of the extraintestinal and psychobehavioral symptoms that can be present with IBS patients. (Halland, Almazar, Lee, Atkinson, Larson, Talley & Saito 2014; Hausteiner-Wiehle & Henningsen 2014.)

Park, Jarrett, Cain and Heitkemper (2008) stated that bloating is a common annoyance for women with IBS. The researchers examined if there was a connection between GI symptoms and psychological distress with the severity of bloating. The study involved 183 women who were aged 18 to 48. The participants were divided into three IBS subgroups: Minimal-Bloating, Mild-Bloating and Moderate-Severe Bloating. As a result of the study, the researchers discovered that more women with Moderate-Severe Bloating had a background of depressive disorders. These participants also had more severe everyday symptoms of anxiety and depression in comparison to the other two subgroups' participants. Additionally, females with moderate to severe bloating stated to have hard stools or straining to have a bowel movement. In conclusion, the severity of bloating is related to other GI symptoms such as intestinal pain, gas and

constipation, further to psychological predicament. The researchers emphasized that considering the severity level of symptoms and psychological distress is essential since it should affect the choice of treatment method.

It has been pointed out that stress affects the subjective experiences of the patients concerning their symptoms. Stress may also influence the IBS patient's health behaviors and the treatment results. (Zernicke, Campbell, Blustein, Fung, Johnson, Bacon & Carlson, 2015.) Additionally, Thompson and Read (2015) noted that socializing with other people might be a common origin for stress. For instance, sharp tone of voice, aggressive temperament, challenging behavior or ignorance from others can change the activity in the nervous system. It was described that people have a tendency to be susceptible to other people's anger or excitement. These emotions might be replicated by mirror neurons and channeled to the viscera, where the intestines are able to "sense" emotions. This feeling sensitivity of the gut is one of the reasons why IBS patients' symptoms are worsened by stress.

3.2 Management of stress and IBS symptoms

Excessive or long-term stress may result as a physical or psychological illness or as an exhaustion. Therefore it is important that people can recognize the symptoms of stress and apply stress management techniques. The physiological responses to stress are for instance elevated blood pressure and pulse, escalated sweating, decreased blood circulation in the skin and diminished activity of the gut. These changes can results as symptoms such as headaches, indigestion and feeling nauseous. Breathing frequency may be escalated and feeling palpitations and different types of aches around the body becomes more common. Emotionally the person can feel anxious, fearful, angry, frustrated or even depressed. These types of feelings can induce the physical symptoms and in some cases, people find themselves even more stressed when they believe they are physically and possibly severely ill. A stressed person might also behave abnormally. They can be more withdrawn, uncompromising and tremulous than before. Being irritable and lachrymose is also common when being highly stressed out. (Mental Health Foundation 2016.)

Stress and stress-related disorders such as anxiety, depression and post-traumatic stress disorder can be medically treated with for example tricyclic antidepressants, atypical antipsychotics and with some versatile agents. Due to limited effect of pharmacological interventions, non-pharmacological approaches in the treatment of IBS are becoming more common. Management of stress and stress-induced responses are important to take care of since stress reduction can decrease IBS symptoms. Methods for stress management are for example good physician-patient –relationship, use of placebo medicines, patient education or counselling, regular physical exercise, proper sleep, hypnotherapy and cognitive behavior therapy as well as relieving stressful situations in life if possible. (Hong-Yan et al. 2012; National Institute of Diabetes and Digestive and Kidney Diseases 2015.)

According to the National Institute of Diabetes and Digestive and Kidney Diseases (2015), health care workers could provide three types of therapies for IBS patients. Cognitive behavioral therapy directs the focus on thoughts and actions. On the other hand, psychodynamic therapy revolves around patient's emotions and how they are affecting the IBS symptoms. This therapy also utilizes relaxation routines and different approaches for stress management. Lastly, the therapist can provide gut-directed hypnotherapy where they use hypnosis to help the patient relax their muscles in the intestines. In addition, Zernicke et al. (2013) suggest that counsellors can also teach mindfulness training where they educate the patient to draw their attention towards sensations that are occurring at that exact moment. By doing this, the patient might avert catastrophizing or relieve worrying which is often caused by overthinking.

Furthermore, Mattila (2010) listed several concrete methods to alleviate stress which can be applied in everyday life situations. Firstly, it is important to share the troubles that are causing stress. It was encouraged that people would discuss about the concerns with their families, friends or colleagues, and try and find possible solutions for the situations. In addition, socializing and taking care of relationships have proven to be an important factor of happiness. Furthermore, studies have discovered that dwelling on problems can be harmful. This habit may predispose people to depression and anxiety which in turn might lead to excess eating and alcohol consumption. Dwelling can also diminish person's self-esteem and problem solving skills. Therefore it is important that instead of dwelling on problems, people would focus on active problem solving. However, if the problems are unsolvable at the moment, people could guide their focus on something else such as listening to music, exercising, movies or socializing. In addition, "charging batteries" is an important key for stress management. People tend

to forget to do things they enjoy doing and which are good for their mental health. It is even suggested that people could create a list of ten things they enjoy and perform these activities during stressful life situations.

Talley (2013) has explained that abnormal signals in the brain-gut-axis can make the brain overactive and hence create stress. One effective way to manage with stress is progressive muscle relaxation which aims to generate calmness and tranquility. This may turn the focus off of the abnormal signals and symptoms and therefore aid a person to cope with IBS. Research that has been carried out on relaxation and its benefits is so far limited, but controlled trials have shown that this method can improve symptoms. Learning to utilize the techniques and become comfortable with them might be time-consuming but it is a technique worth of testing. “Progressive muscle relaxation is a systematic way of relaxing all the muscles of the body.” Typically the exercise is started with the upper limbs, continuing to different large muscle groups. The purpose of the exercise is to first tense and then relax the muscles, and to go through every muscle group in the body. The rehearsal usually ends with lower limbs.

Stress can be diminished with exercise which may also support GI function. Previous studies have shown a positive correlation with physical activity and alleviation of symptoms. For instance, yoga has been found to be beneficial for symptom management for both adults and youngsters. A study which was carried out for two months showed that patients who practised yoga twice a day, had equivalent enhancement for IBS symptoms compared with a control group. The control group’s patients were treated daily with 2-6mg of loperamide which is a medicine for treating diarrhea. (Yoon, Grundmann, Koepp & Farrell 2011.)

4 PURPOSE OF THE STUDY AND RESEARCH QUESTIONS

The purpose of this study was to gather information from diagnosed IBS patients and to investigate if they had experienced that stress affects their IBS symptoms. The author also studied if patients had received patient counselling about stress and what stress related topics participants would like to include in the counselling in future. The aim was to gain information for the development of IBS patient counselling.

There are two main questions that the author wanted to investigate in her study. The questions are as follow:

1. What kind of experiences do irritable bowel syndrome patients have related to stress?

2. What kind of patient counselling would patients like to receive from health care professionals about stress related factors?

5 METHODOLOGY AND DATA

There are some studies carried out about patient experiences on how IBS patients' symptoms are affected by stress, yet many of them were carried out before the year 2000. The author did not use these studies in the thesis in order to maintain reliability. In addition, there is a lack of information if patients are receiving adequate counselling after receiving IBS diagnosis and whether the counselling includes stress related factors. Due to limited amount of previous research, the author chose to execute this study with qualitative research approach.

5.1 Qualitative research

"Qualitative research is a form of social inquiry that focuses on the way people make sense of their experiences and the world in which they live." This study method can be approached from different aspects but most of them have the same aim – to gather knowledge about a phenomenon experienced by individuals, groups or culture and to understand, portray and interpret the findings. The research method can investigate for example behavior, feelings or experiences. (Holloway & Wheeler 2013, 3-4). In this study, the author wanted to focus on patients' experiences, thus qualitative approach was chosen to suit the purpose.

5.2 Data collection

The study was conducted as an open Internet-survey through Webropol program. According to Timmins (2015), it is defined that a survey is "a systemic collection and analysis of data relating to the attitudes, living conditions, opinions, etc, of a population… taken from a representative sample of the latter". By conducting a survey, the researchers will obtain knowledge of the characteristics or perceptions of the whole population (for example scrub nurses). Generally, when performing a non-experimental research, the data is collected only once with the use of a questionnaire to identify elements of the participants' lives.

A simple questionnaire was created and utilized in the process of data collection. The questionnaire included one closed-ended question to eliminate possible answers from non-diagnosed IBS patients. This was done to ensure the validity of the study. However, other three

questions were open-ended so that participants were able to write and describe their experiences as they felt appropriate. The purpose of question two was to give an opportunity to participants to explain how stress might affect their IBS symptoms. Third question was utilized to examine if patients had received patient counselling that had included information about stress. In the last question, participants were able to describe what topics about stress they would like to include in the IBS patient counselling in future. The questionnaire was developed in Finnish and the participants answered it in Finnish. The data was then translated into English by the author, so that quotations from the survey answers could be used to support the findings of the study.

The author utilized a pilot test to ensure that the questionnaire was easily understandable for the participants. The Finnish questionnaire was distributed to three people who were diagnosed with IBS. Based on the comments of pilot testers and guidance of supervising teacher, the questionnaire was modified into its final form. Hirsjärvi et al. (2009) state that for example questionnaires have to be formed in a way that they support the validity of the research. Validity signifies the degree of how well the measurement instrument or method measures what it is planned to measure (Timmins 2015). It was also noted that reliability measures the consistency and accuracy of the findings. This means that a questionnaire has to consist of questions that participant can easily understand and answer so that misunderstanding can be avoided since it could reduce the reliability of the results.

The data was collected through a Facebook group called FODMAP Suomi. FODMAP Suomi – group can be identified as a peer support group for IBS patients and people who are generally interested in the topic. This group served as a focus group for the study. According to Holloway and Wheeler (2013), a focus group consists of a number of people who have a common experience or characteristics. The purpose of using focus groups is to gather in-depth information, ideas and thoughts from a specific topic that the author wants to investigate. Generally the idea is for the researcher to interview the focus group, though in this study the data was collected with a simple questionnaire that the participants voluntarily fulfilled. Since there is no official association for IBS patients in Finland, the author decided to collect the data through the FODMAP Suomi peer group which has a large number of members. If the author had not used this Facebook group as a source of participants, it might have been challenging to find respondents elsewhere.

An electronic link for the survey was published in the FODMAP Suomi group wall before the survey was opened. After the respondents had completed the questionnaire, it was automatically received by the author. The collection of data was conducted between 6th of September and 10th of September 2016.

5.3 Data analysis

According to Holloway and Wheeler (2013), qualitative data analysis generally follows a certain pattern which includes the following steps; The researcher transcribes the interviews or questionnaires and then organizes the data in a way that it can be processed through many times. Furthermore, if the researcher intends to interpret the data, categorizing is an advisable step which leads to generating themes that are found in the research. After these stages the researches is able to describe the phenomenon that is under investigation.

The data was analyzed with a method called inductive content analysis which is a method to interpret meanings and describe visible components from collected text data. In content analysis, the first step is to decide the unit of analysis which is the object the author desires to study. The next steps of the analysis were the reduction of collected data, clustering and abstraction. During the process of reduction, the analyzer can either summarize the data or fraction it into different divisions. The reduction is done by transcribing or coding the most significant discourses from the data. The researcher can utilize different tools, for instance condensed meaning unit. A condensed meaning unit is a summarized pattern of words or statements that are associated to a same basic meaning. The process of reduction itself is guided by the research question. After reduction, the analyzing process continues with clustering which means that analyzer finds similarities and differences from the abstracted data. Then the similar discourses are categorized into different groups. Categories are an essential element in qualitative content analysis because one category includes a group of material that shares common content. Lastly, in the final step of the analyzing process, the data is abstracted. This means that the data is grouped together under higher order headings. (Graneheim & Lundman 2003; Tuomi & Sarajärvi 2013, 95; Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs 2014.)

In this study, the author received 29 fulfilled questionnaires from diagnosed IBS patients which were used as units of analysis. No halted questionnaires were submitted and all 29 participants

reported to be diagnosed with IBS based on questionnaire question 1. Consequently, the author utilized all submitted survey answers in the study. Since the questionnaire was published and answered in Finnish by the respondents, the author firstly translated the material into English. However, the author did comprehend that due to translation some of the information might be slightly changed. This risk was taken into account during content analysis and while writing the findings of the study. To minimize the risk of mistranslation, the author used proper Finnish-English dictionaries to help with the translations. (Appendix 3.)

The author started the translation process and data analyzing in mid-September. The author printed the survey answers into A4 pages and the amount of pages were eight. Firstly, the questionnaire answers were divided into three categories according to the survey questions. Then the author started reduction of the material by utilizing condensed meaning units which were written on separate A4 pages. Then the condensed meaning units were clustered and categorized into separate groups. Finally, the different categories were abstracted into a correct high-rank order. In addition, the author created three tables to show the data analyzing process and to utilize them as mind-maps while writing the findings of the study. (Appendix 4.)

6 FINDINGS OF THE STUDY

This chapter presents the findings of the study. The results are presented in three subheadings according to the three open-ended survey questions (Appendix 4). The findings include quotations from the participants' survey answers to support the validity of the results.

6.1 The effect of stress on IBS symptoms

The first open-ended question of the study was used to determine if IBS patients feel that stress has an effect to their IBS symptoms. Based on the survey answers, most of the respondents reported that stress worsens their IBS symptoms or can cause GI symptoms. Few of the participants did not further explain how their symptoms are worsened but most commonly the respondents noted that stress worsens bloating or flatulence, diarrhea and abdominal pain. The survey revealed that ten respondents experienced loose stomach and diarrhea as a result of stress. On the contrary, two participants described that stress resulted as a worsening of constipation. In addition, stomach cramps and abdominal pain were reported by eleven patients, and some of them also experienced diarrhea or constipation.

"It worsens the symptoms. Stomach is loose and achy."

Some of the participants had also noticed that stress can change their appetite which could be either increased or decreased. They also reported that stressing about diet can also result as GI symptoms, and one partaker described that her/his digestion seems to become slower during stressful situations. A few of the respondents explained that they can have stress with the diet they are following, since it might be uncertain if appropriate food ingredients are available during travelling. One partaker explained that eating abroad can be troublesome because the Fodmap diet is not well-known internationally. Therefore, some restaurants are not sure, if they can serve Fodmap appropriate food and misunderstandings are common. For example, the traveler cannot necessarily be sure, if the served dish includes for instance onions. In addition, two of the respondents emphasized that during their stressful periods of life, it does not matter what they eat. They described that even Fodmap diet does not help with the symptoms, if stress is strongly present.

"My stomach becomes achy from everything that I eat, but without stress my stomach feels well when applying fodmap diet."

It was also evident that stress had also resulted as heartburns, nausea, chest area distress, increased bowel sounds and general malaise. One of the survey participants had experienced symptoms of gastro paresis due to stress for approximately 30 years. This means that the intestines become lethargic and do not function properly. Food will stay in the stomach and cause the abdomen to swell a lot. This later on causes her/him strong medicine resistant headache since no medicines will reach the intestines. The eyes become sensitive to light and without a possibility for sleep, she/he will find her/himself on the floor and start vomiting.

> *”It worsens them. Stress makes my stomach even more upset, my chest feels more distressed along with other bloating, and symptoms of heartburn get worse!”*

In addition to the wide range of symptom aggravations, it was apparent that the severity of the effect of stress varied considerably between different individuals. A few participants emphasized that the severity of symptoms can become intolerable due to stress and managing normal activities of daily living can become challenging. In the extreme cases, some patients had to stay indoors due to severe diarrhea or abdominal pain.

> *“It worsens the situation – it instigates the symptoms and therefore causes more stress. It easily creates a circle and I might not necessarily dare to leave from home.”*

On the other hand, there were five participants that reported to experience no direct effect from stress. Three of them stated to feel no effect at all and one of them described that her/his stomach reacts to stress and excitement, but she/he can easily control it with different exercises. This respondent had received counselling for stress management years before being diagnosed with IBS and she/he had attended mindfulness-groups, done relaxation exercises and etc. The partaker found these techniques helpful for overall life management and therefore did not experience that stress would affect to IBS by itself. However, the fifth participant noted, that in her life stress does not directly cause changes to the IBS symptoms. This respondent described that work stress affects to other parts of life such as quality of sleep, eating habits and exercising routines. As a result, unsatisfactory sleep, irregular eating and exercise rhythms and wrong type of food were noticed to cause the stomach to become upset.

6.2 Experiences of patient counselling including stress

The questionnaire included an open-ended question (Appendix 3) and its purpose was to investigate if patients had received patient counselling about stress as a part of their IBS. The study showed that 19 of the participants had not received any type of patient counselling after being diagnosed with IBS. These participants clearly stated, that they were not educated about food, medicinal options, and stress or about anything else. A few of the respondents replied that their treating doctors had told them to look for more information themselves on internet yet without giving any instructions on what to search for. Two patients had been instructed to use either Imodium or Agiocur for the treatment of diarrhea and one respondent was advised about diet and usage of fiber. Other two had met with a dietician and one patient was waiting for the upcoming appointment. In conclusion, it was obvious that most of the partakers were very disappointed with their treatment and lack of proper patient counselling.

> *"I got nothing. All patient counselling, received from doctors, nurses and dietician, related to IBS has been very negligible. I have had to find everything myself."*

> *" Nothing. After the endoscopy the doctor announced that I have IBS and that there is no treatment for it. Take Imodium for diarrhea and eat what you can. I looked for information online and found different natural products (silicic acid gel, boulardii) as well as instructions for Fodmap- diet."*

In addition, the author noticed that only four participants reported that their treating physician had mentioned stress during their patient-physician discussion. However, the discussions about stress were left short. Some doctors had mentioned that stress can worsen the patient's IBS and some stated that the patient should try to reduce their stress or not stress at all. Only one physician had mentioned that it would be important to have enough sleep and rest. Nevertheless, the patients were not actually counselled or guided about stress management or about the techniques they could utilize in everyday life. On the other hand, one of the participants replied that she/he had not yet sought help for stress.

> *"Not any type of counselling. The doctor said that stress also affects irritable bowel, but I did not receive more counselling than that."*

The study also showed that one of the partakers had not received counselling from the treating physician. A health therapist gave information on the importance of stress management and avoidance of stress. Another respondent emphasized that due to her combination of IBS and

some other diseases, it is important that IBS is not separated and treated individually. In this example, the respondent said that she/he has a good caring team and that her/his condition is treated in a holistic manner. Moreover, one of the participants stated to be very satisfied with the patient counselling she/he had received. However, this participant did not mention, if stress was included in the counselling. This particular response included examples such as gaining accurate diet instructions from a dietician, meeting with a physiotherapist who guided with pelvic floor muscle exercises and etc., as well as having an opportunity to try devices that give electrical impulses to muscles. On the contrary, one participant had sought help for stressful life situation from occupational health but was disregarded.

> *"I have not had counselling. I sought help and advices from occupational health for challenging work situation and feeling of exhaustion, the symptoms were put on the blame on IBS, although conversely stress triggered a difficult stomach catastrophe."*

6.3 Patients' suggestions for IBS stress counselling

It was observable that the participants were strongly divided into different groups based on their ideas about IBS stress counselling. (See appendix) In the first group, three of the respondents did not answer to the study question or reported that they do not understand the question itself. In addition, a second group with three participants did not have a need for stress counselling. Two of these participants explained that since stress seems to have no effect on their IBS symptoms, stress counselling is not needed. The other participant also stated that the stressors in her/his daily life cannot be affected in any means, hence there is no opportunity to decrease the stress. Furthermore, the third partaker seemed to doubt stress counselling in general.

> *"Could there be any (topics)? Stress is so individual and in my opinion, it is difficult to control stress with any general instructions."*

On the other hand, two patients were categorized as contented respondents. They reported that they had already received very good and satisfying counselling where different topics were widely discussed. They also stated that they were offered a possibility to ask questions during counselling. On the contrary, one of the respondents stated that any type of counselling would have been good since she/he had not received counselling after the diagnosis. Another partaker (referred as disappointed patient in Appendix) could not tell what topics she/he would have wanted to discuss about. The participant explained that in many cases, the physicians

have caused even more stress and approached the patient in an unprofessional way during the patient-physician discussion.

> *"I cannot tell. Many times the doctors cause even more stress with their attitudes, for example by blaming me to have an eating disorder after seeing me once and after calculating my BMI. Otherwise the dismissive and inculpatory way to approach a patient who is tired and in pain feels bad."*

However, the rest of the participants had several topic suggestions for future IBS patient counselling related to stress. Firstly, it was suggested that the patient would be counselled about how stress can affect IBS and its symptoms, or what are the possible outcomes of prolonged stress. It was also noted that the counsellor could educate patients on how to recognize that a person is having stress. Nevertheless, the most common suggestion for stress counselling topic was management of stress. These participants emphasized that they would like to receive counselling where they are given concrete options on how to avoid, tolerate or reduce stress.

> *"They could have told that it (stress) can affect and they could have advised how to prepare for it, and given instructions on how to handle stress."*

The respondents gave many precise suggestions which could be included in the patient counselling in future. Three participants proposed that education about mindfulness and meditation could be considered. For instance, two of these partakers reported to have practiced mindfulness, and have found it very helpful for IBS management. In addition, respondents were interested to hear more about different physical exercises which have been discovered to help with stress management. The study showed that many of the partakers were especially interested in yoga or regarded it as a helpful form of exercise. At least three different types of yoga practices were tried out by the patients and all of them were found beneficial. One of these respondents even propounded that patients could be guided to courses which focus on relaxation methods. It was also suggested that patients could receive more information about various natural products which have been proven to help with the management of stress and its symptoms. In addition, one of the partakers mentioned that counsellor could give tips on how to calm down the vagus nerve.

> *"Guidance to relaxation management course or something like that. I have found kundalini yoga, which helps a lot in stress management and body maintenance."*

Furthermore, some of the respondents were interested in the liaison of IBS and stressful work. They were wondering how to combine work with challenging IBS symptoms. One participant

raised a question of how shift work can affect IBS since it can cause a physical stress condition to the body. The partaker further wondered if therapy has an effect on mental health and could be a basis for justification for admission of therapy. It was also apparent that patients were interested in the combination of stress and Fodmap diet. Some patients explained that following the Fodmap diet causes extra stress and they would need help with it. For instance, it was proposed that aiding to make the diet more ordinary and simple could also affect the level of stress. It was also suggested that the diagnosing physician could send the patient further to a dietician's appointment. One of the participants emphasized that the physician should discuss with the patient about stress in general and try to find out the current status of the patient.

> *"Overall, the doctor should be asking if the person is experiencing her/his life stressful, are there stress factors, and can they be affected and about the state of one's health in general (including sexual health because IBS can affect sexual health, which may also affect by adding stress if there are problems with something)."*

In conclusion, most of the participants experience that stress can affect IBS symptoms. It was also observable that most of them had not received any type of patient counselling, not to mention stress. Based on the answers of approximately two thirds of the participants, several topics which could be included in the IBS patient counselling were identified.

7 DISCUSSION

7.1 Discussion of the research method and limitations

The author chose to use qualitative research approach since it is most suitable for investigating experiences and emotional meanings. When the author chose to carry out a WebroPol-survey, there was a challenge to find proper source of possible participants. There is no official association for IBS patients in Finland, so the author had to find these patients through another source. The Facebook group FODMAP Suomi was found and the author ensured it was a peer support group for especially IBS patients. The suitability to use the group as a source of potential participants was confirmed from the supervising teacher. The peer group also included members who were not actually diagnosed with IBS. Due to this, the author restricted the study to concern only patients with an actual diagnosis so that the validity of the study was ensured.

According to Holloway and Wheeler (2013) the researcher has to realize that qualitative study might produce a lot of data and lack of time is possible. Conducting the investigation takes time and author should be well prepared. The amount of data and the applicable time which author has should be reconciled. While carrying out the study, the author was aware of these possible issues. Due to the fact that FODMAP Suomi is a remarkably active group, the author believed that a long survey opening time would generate a lot of data to analyze. Therefore, the author chose with the guidance of the supervising teacher, that the survey was open for approximately five days. As suspected, the number of respondents grew high up to 29, considering that even a few answers in qualitative research tend to generate a lot of data. However, the author analyzed all survey answers without restrictions, since they included various different aspects that were significant for the study. Time management issues became present, but the author ensured that enough time was used to efficient and reliable content analysis.

7.2 Discussion of the findings of the study

The purposes of this study were to gather information and to investigate if IBS patients experienced that stress had an effect on their IBS symptoms. The author also wanted to study if

patients had received patient counselling about stress when they were diagnosed with the impediment. In addition, the author was interested to describe what stress related topics the patients would like to include in the counselling of stress. The first open-ended question (questionnaire question 2, Appendix 3) sought answers to the first research problem which was "What kind of experiences do irritable bowel syndrome patients have related to stress?" According to the results, most of the participants stated that their IBS symptoms are aggravated by stress. Most commonly stress increased GI tract symptoms such as bloating, diarrhea, constipation, flatulence and abdominal pain. Some the respondents also described that stress affects other types of symptoms such as increase or decrease in appetite, heartburn, nausea and etc. Furthermore, only a minor number of participants reported that their symptoms were not affected by stress at all. (Appendix 4/1.) These findings are consistent with the previous studies which have shown that IBS is strongly affected by psychological stress in childhood or adulthood. Stress can affect the intestinal sensitivity, motility, secretion and permeability. These changes can further on induce the characteristic GI symptoms of IBS. In addition, the severity of stress effect may vary between different individuals. For instance the severity of bloating, straining to defecate and constipation are associated with the level of psychological distress. (Hong-Yan et al. 2014; Park, Jarrett, Cain & Heitkemper 2008.)

Moreover, questions number 3 and 4 of the survey questionnaire sought answers to the second research question which was: "What kind of patient counselling would patients like to receive from health care professionals about stress related factors?" (Appendix 3.) To obtain better understanding of the current situation of patient counselling about stress, the author utilized question 3 to receive descriptions of previous experiences. The most significant finding was that most of the respondents had not received patient counselling at all. Some participants had briefly mentioned about stress, yet no proper counselling about the effect or management of stress was given. On the other hand, two of the partakers reported to be satisfied with their patient counselling experiences. (Appendix 4/2.) However, it can be deduced that the significantly high amount of patients with no patient counselling experiences could potentially be resulted from the type of study that was utilized. The author acknowledged that this study could especially draw the interest of patients, who are generally unsatisfied with their IBS treatment and who saw an opportunity to make a difference by answering the survey. Due to this possible aspect, it could be proposed that further studies could investigate more about the patient experiences and satisfaction of IBS patient counselling.

Based on the findings of this study, most of the survey participants would be interested in patient counselling about stress and many suggestions for stress topics were presented. Firstly, it was obvious that respondents would like to gain more knowledge about the connection between IBS and stress, and to know what can be the possible effects of stress on their IBS. Secondly, it was stated that general instructions for stress management could be included in the counselling. Furthermore, some of the participants came up with more detailed suggestions such as yoga, use of natural products, how to calm the vagus nerve, guidance to relaxation courses and etc. On the other hand, some participants experienced that counselling about stress would be in vain since stress had not affected their IBS symptoms. (Appendix 4/3.) According to the previous studies, IBS patient could greatly benefit from different stress management methods to alleviate their stress and hence their IBS symptoms. For instance, proper sleep and physical exercise such as yoga may alleviate the level of stress. For example yoga exercises among adults and youngsters have been shown to alleviate IBS symptoms by supporting GI function. Other effective stress management methods such as hypnotherapy or cognitive behavioral therapy can help the patient to focus their thoughts, actions and emotions to create a better understanding how their IBS is affected by stress. Furthermore, patient education or counselling is proven to be another great way to reduce patient's stress and give advices for future disease management. (Hong-Yan et al. 2014; National Institute of Diabetes and Digestive and Kidney Diseases 2015; Zernicke et al. 2013.)

All in all, the aim of this study was achieved and the author gained a lot of information from the participants. These results can be utilized in the development of IBS patient counselling in future, since they essentially present the fact that there is a need for IBS stress counselling.

7.3 Discussion of ethics and validity

The study benefited the participating unit (clinic of gastroenterology) by providing information about IBS patients' experiences on stress and patient counselling. The aim of this study was to generate information which could be utilized in the development of IBS patient counselling and this aim was achieved. The results of this study were not gathered through the participating unit, but through an open online questionnaire. Therefore, the findings are not describing the type of counselling the participating clinic is providing.

The reliability of the study was ensured by utilizing current studies that were published between 2008 and 2016. In addition, the author used only scientific research studies, official reports or information from association webpages. The reference materials were cited accurately and misunderstandings were avoided.

The author was in contact with the administrator of FODMAP Suomi –group throughout the year 2016 and research permit was granted by the administrator before the Webropol survey was opened. A cover letter was published in the wall of FODMAP Suomi one day before the survey opening and the author gave an opportunity to contact her via email or facebook with any concerns the members could have had. The electronic link to the survey was published in the facebook group before the survey was opened and participants were able to answer the questionnaire anonymously. The questionnaire was pilot tested by sample participants to eliminate possible misunderstandings before the actual survey was carried out.

The cover letter explained that the participation was completely voluntary and that they had a possibility to refuse to give information or withdraw from the study at any point. According to Polit and Beck (2008), the participants have the right for full disclosure which means that the researcher has to describe the nature of the study completely and clearly. Disclosure was provided in the cover letter and the author sent further information to those who contacted her by email or by commenting on the Facebook cover letter or survey link. The data was processed and analyzed confidentially, only by the author of the study and the data was disposed of properly after the study had been conducted.

8 CONCLUSIONS

Currently, it is internationally recognized that irritable bowel syndrome is a common functional disturbance of the intestines. In Finland, it affects a large number of the population and the severity of the impediment can range from mild to severe. For some patients, the syndrome is dramatically affecting their quality of life. During the short history of IBS research, the scientists have generated a lot of new information that could be utilized in the treatment and patient counselling of IBS patients. Due to the fact that IBS is not a curable disease but rather a chronic condition, it would be important that the patients are aware of the different treatment options. The scientific literature emphasizes more on dietary and pharmacological interventions, yet it has been proven that stress can be a common trigger or aggravator for IBS symptoms. In addition, the public discussions and the findings of this study are supporting this conception.

The purpose of the present study was to examine the patient counselling experiences especially related to stress. The study indicated that most of the participants were remarkably unsatisfied with the patient counselling they had been provided with after their diagnosis. Most of the respondents had not received counselling at all. A few of them explained that after the diagnosis had been set, the physicians had casually noted that the disease is incurable. Some reported that physicians had encouraged the patients to search information themselves without giving any instructions what to search for. It was evident that in most of the cases, the patient counselling did not include any material about the effect of stress on IBS or stress management instructions. However, approximately two thirds of the respondents were interested in the association of stress and IBS. These participants also came up with many possible stress topics that could be included in the patient counselling.

In conclusion, the study indicated that there was an actual need for patient counselling about stress among IBS patients. The aim of the study was to gather information for the development of IBS patient counselling and the results of this study could be utilized for instance in primary health care and gastroenterological units. As an implication to nursing practice, this study shows the importance of proper patient counselling which could be more encouraged in the work units. Patient counselling is one of the main responsibilities of a nurse, therefore further attention should be guided towards this patient group. Further studies may be directed more towards overall patient counselling experiences and patient satisfaction of IBS patients. Future

research could also investigate how efficiently these patients are treated and counselled, since as a common impediment IBS can become highly expensive for the health care system.

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Centria
AMMATTIKORKEAKOULU

TUTKIMUSLUPA-ANOMUS

Organisaatio, jolle anomus osoitetaan FODMAP Suomi

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Tutkimuksen nimi Stress and Patient Counselling Associated with Irritable Bowel Syndrome – A Qualitative Study Based on Patient Experiences

Tutkimuksen tarkoitus Selvittää, onko stressillä vaikutusta IBS oireiluun sekä kartoittaa mitä stressiin liittyviä aiheita potilaat toivovat sisällytettävän potilasohjaukseen.

Tutkimuksen kohderyhmä Diagnosoidut ärtyvän suolen oireyhtymän potilaat

Aineiston keruun arvioitu ajankohta 06.09.2016 – 10.09.2016

Tutkimusmenetelmä Kvalitatiivinen tutkimus - Avoin internet-kysely ja sisällön analyysi

Tutkimussuunnitelma hyväksytty 18 / 12 20 15

Tutkimuksen ohjaaja Maria Björkmark

Lupa myönnetään

paikka Helsinki **aika** 06 / 09 20 16

☒ **anomuksen mukaisesti** ☐ **muutosehdotuksin** ☐ **hylätty**

Luvanmyöntäjän allekirjoitus Annemari Eerola

LIITTEET
☐ **Tutkimussuunnitelma**
☑ **Kysely/haastattelulomake**
☑ **Muut liitteet, mitkä** saatekirje

COVER LETTER – SAATEKIRJE APPENDIX 2

Hyvä vastaanottaja,

Olen neljännen vuoden sairaanhoitajaopiskelija ja opiskelen Centria-ammattikorkeakoulussa englanninkielisellä koulutuslinjalla Kokkolassa. Teen opinnäytetyötä ärtyvän suolen oireyhtymästä, josta käytetään lyhennystä IBS (Irritable Bowel Syndrome).
Opinnäytetyön tarkoituksena on kerätä tietoa potilaskokemuksista ja selvittää, kokevatko vastaajat, että stressillä on vaikutusta IBS oireiluun. Lisäksi tutkimuksessa on tarkoituksena saada selville, ovatko potilaat saaneet potilasohjausta stressistä ja minkälaista potilasohjausta he toivoisivat saavansa stressistä tulevaisuudessa. Tutkimuksen tavoitteena on kerätä tietoa, jota voidaan vastaisuudessa hyödyntää potilasohjauksen kehittämisessä.

Tutkimusaineisto kerätään avoimena internet-kyselynä WebroPol-ohjelman kautta, johon FODMAP Suomi –ryhmän jäsenet voivat osallistua vapaaehtoisesti. Osallistujien tulisi olla IBS-diagnoosin saaneita henkilöitä, jotta tutkimus säilyy luotettavana. Kyselylomake on suomenkielinen ja se sisältää kolme avointa kysymystä, joihin vastaaminen vie keskimäärin 10-15 minuuttia. Saadut vastaukset analysoidaan luottamuksellisesti ja yksittäisen vastaajan tiedot eivät ole tunnistettavissa. Vastaaminen tapahtuu nimettömänä ja osallistujalla on myös oikeus keskeyttää kyselyyn vastaaminen, jos hän ei haluakaan ottaa osaa tutkimukseen.
Kysely avataan Webropol-ohjelmaan, johon lähetetään kyselyn vastausajan alkaessa internetlinkki FODMAP Suomi –ryhmän facebook-seinälle. Vastausaika kyselyyn alkaa tiistaina 06.09.2016 klo 09.00 ja vastausaika päättyy lauantaina 10.09.2016 klo 21.00. Jos haluatte lisätietoja tai teillä on kysyttävää, ottakaa ystävällisesti yhteyttä sähköpostitse allekirjoittaneeseen. Arvostan suuresti osallistumistanne tämän opinnäytetyön toteutumiseen.
Kiitos vastauksestasi!

Ystävällisin terveisin,
Carola Kortet
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Degree Programme in Nursing
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THESIS SURVEY QUESTIONNAIRE – STRESS ASSOCIATED WITH IRRITABLE BOWEL SYNDROME

1. Are you diagnosed with irritable bowel syndrome?
    - Yes
    - No

2. How does stress affect to your irritable bowel syndrome symptoms?

3. What kind of patient counselling have you received about stress as a part of irritable bowel syndrome?

4. What stress related topics would have you wished to been included in the patient counselling?

OPINNÄYTETYÖN KYSELYLOMAKE – STRESSI OSANA ÄRTYVÄN SUOLEN OIREYHTYMÄÄ

1. Onko sinulla diagnosoitu ärtyvän suolen oireyhtymä?
    - Kyllä
    - Ei

2. Miten stressi vaikuttaa ärtyvän suolen oireyhtymän oireisiisi?

3. Minkälaista potilasohjausta olet saanut stressistä osana ärtyvän suolen oireyhtymää?

4. Mitä stressiin liittyviä aiheita olisit toivonut potilasohjauksen sisältävän?

TABLE 1. Effects of stress to IBS symptoms.

Original expression	Condensed meaning unit	Subcategories	Main category
"I haven't noticed that stress would affect to my symptoms."	No effect at all	No straight effect to symptoms	Possible effects of stress to IBS symptoms
"Stress doesn't directly affect to the symptoms yet everything that is connected to stress has an effect. For example work stress affects to quality of sleep, to diet habits and to lack of exercise."	Indirect effects to symptoms through e.g. sleeplessness, lack of exercise or poor eating habits.		
"The symptoms get worse immediately, stomach becomes upset and diarrhea gets worse."	GI tract symptoms are aggravated by stress	Effect of stress felt by respondents	
"Bloating and especially nausea and lack of appetite will increase."	Stress affects to other IBS symptoms		

TABLE 2. Participants' experiences about patient counselling.

Original expression	Condensed meaning unit	Subcategories	Main category
"I didn't receive patient counselling at all."	No counselling given about IBS at all	No proper patient counselling given	Patient counselling
"Counselling did not include information about stress."	No counselling given about stress		
"I was briefly told about Fodmap-diet and given a brochure."	Counselling about diet	Patient counselling about other factors that can help with the management of symptoms	
"Take Imodium for diarrhea and eat what you can."	Counselling about medicines		
"I visited a dietician who offered various types of diet instructions."	Counselling from other professional	Patient counselling about stress	
"The patient counselling has been good so far."	Satisfaction to counselling		
"I have not yet sought help for stress as a part of IBS."		Participant who had not sought help for stress	
"Once there wasn't information for example about Fodmap-diet."		Participant who received diagnosis when no sufficient information about IBS was available	

TABLE 3. Participants' suggestions for future patient counselling about sress.

Original expression	Condensed meaning unit	Subcategories	Main category
"I do not understand the question?	Participants who did not understand the question/didn't write anything	No answer to the question	Suggestions for future patient counselling about stress
"Could there be any (topics)? Stress is so individual and in my opinion, it is difficult to control stress with any general instructions."	If stress doesn't have an effect, no need for counselling	No need for counselling	
"Everything relevant has been gone through, and I have had a possibility to point out things and ask questions"	Have received good and satisfying counselling which included several topics	Contented respondents	
" I cannot tell. Many times the doctors cause even more stress with their attitudes, ... Otherwise dismissive and inculpatory way to approach a patient who is tired and in pain feels bad."	No idea about possible topics and hurt feelings due to unprofessional approach from physicians.	Disappointed patient	
"About the connection of stress and IBS in general."	The relation of stress to IBS and possible affect	Suggestions for stress counselling topics	
"Guidance to relaxation management course or something like that."	Precise management methods		
"About natural products, relaxing physical hobbies (yin-yoga and etc."			