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Experiences of dietary guidance among patients with Inflammatory Bowel Disease: A qualitative study

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The logo for OsloMet University of Applied Sciences, featuring the word "OSLOMET" in a bold, black, sans-serif font, tilted at an angle, set against a bright yellow rectangular background.

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Table of content

1.0 Organization of the thesis.....	1
2.0 Introduction.....	1
3.0 Aim of the study.....	5
4.0 Theoretical framework.....	5
4.1 Nutrition communication.....	5
5.0 Tailored dietary guidance.....	6
6.0 Barriers to nutrition communication.....	7
6.1 Health literacy.....	7
6.2 Time during consultations.....	8
6.3 Patient-provider communication.....	8
7.0 Multidisciplinary care.....	8
8.0 Nutritional information sources - needs and preferences.....	9
9.0 Method.....	11
9.1 Choice of methodology.....	11
9.2 Interviewing.....	11
9.3 Analysis and transcription.....	13
9.4 Validity and reliability.....	15
9.5 Ethical considerations.....	16
10.0 Summary of results.....	16
<i>Experiences of dietary guidance from clinical dietitians.....</i>	<i>17</i>
11.0 Methodological discussion.....	17
11.1 Individual interviews.....	17
11.2 Choice of inclusion criteria.....	19
11.3 Recruitment strategy.....	19
11.4 Analysis.....	19
11.5 Ensuring validity and reliability.....	20
11.5.1 Validity.....	21
11.5.2 Reliability.....	21
12.0 Discussion of the results.....	22
13.0 References.....	27
14.0 The article.....	37

List of tables

Part 1:

Table 1: Example of how codes are put into sub-themes and main themes

Part 2 (article):

Table 1: Background data of the participants

Table 2: Themes and subthemes

List of appendices

Appendix 1: E-mail send to Norwegian centre of research data (NSD) to ask to include people over 50 years old

Appendix 2: Interview guide before revision

Appendix 3: Interview guide after revision

Appendix 4: Original application to NSD

Appendix 5: Consent form

List of abbreviations

CD: Crohn's disease

UC: Ulcerative colitis

IBD: Inflammatory Bowel Disease

LMF: Norwegian national association against digestive diseases

NSD: Norwegian centre for research data

Summary

Background: The prevalence of Inflammatory Bowel Disease (IBD) increases rapidly worldwide. Dietary guidance is an important pillar in the follow-up of patients with IBD. To provide patients with efficient dietary guidance, we need more knowledge about how they experience dietary guidance. This study explores how patients with IBD experience dietary guidance provided by different health professionals.

Methods: Semi-structured, individual interviews were conducted with 10 patients (1 male, 9 females) with IBD in the area of Oslo, Norway from October 2020 to December 2020. Participants were diagnosed with IBD for at least 6 months. The analysis of the interviews was guided by thematic analysis.

Results: In general, patients expressed a need for more dietary guidance. Participants met various health professionals during their follow-up, such as general practitioners, gastrologists and, sometimes, clinical dietitians. Some patients strived to receive follow-up by a clinical dietitian. They often experienced that health professionals had little knowledge and motivation to provide them with dietary guidance related to IBD. They often felt left alone and self-responsible to find dietary guidance in other informational sources or tried different diets on their own.

Conclusions: This study indicated that patients with IBD need more dietary guidance from health professionals. Based on the participants' responses health professionals meeting patients with IBD should get more motivated and get more knowledge to provide dietary guidance related to IBD.

Sammendrag

Bakgrunn: Prevalensen av inflammatorisk tarmsykdom (IBD) har hatt en kraftig økning på verdensbasis. Kostholdsveiledning spiller en viktig rolle i oppfølgingen av IBD pasienter. For å kunne gi pasientene effektiv kostholdsveiledning trenger vi mer kunnskap om hvordan pasienter med IBD opplever å få kostholdsveiledning. Målet med denne oppgaven er å utforske hvordan kostholdsveiledning fra ulike typer helsepersonell oppleves av pasienter med inflammatorisk tarmsykdom (IBD).

Metode: 10 pasienter med IBD ble intervjuet (1 mann, 9 kvinner) ved hjelp av semi-strukturerte intervju i Osloområdet i Norge fra oktober 2020 til desember 2020. Tematisk analyse ble brukt for å analysere intervjuene.

Resultater: Generelt, uttrykte pasientene at de ønsket mer kostholdsveiledning. Deltakere møtte ulike typer helsepersonell i løpet av oppfølgingen sin som fastlegen, gastroenterologer, og noen ganger klinisk ernæringsfysiolog. Noen pasienter ønsket oppfølging hos en klinisk ernæringsfysiolog. Mange pasienter fikk inntrykk av at helsepersonellet hadde liten kunnskap og motivasjon til å gi dem kostholdsveiledning for IBDen. De følte at de ofte ble etterlatt til seg selv og at de selv måtte finne kostholdsinformasjon fra andre kilder eller prøve ulike dietter på egenhånd.

Konklusjon: Denne studien viste at kostholdsveiledning ofte er fraværende eller utilstrekkelig for IBD pasienter. Basert på intervjuene med deltakerne er det behov for at helsepersonell, som er i kontakt med pasienter med IBD, får mer motivasjon og kunnskap i å gi dem spesifikk kostholdsveiledning.

1.0 Organization of the thesis

This thesis is written in an article format. In the first part, the study's theoretical and methodological background will be presented. Followed by a short summary of the main findings, a detailed methodological discussion and a discussion of some of the findings in view of the theoretical background. Further, additional results and the discussion of these results will be presented in the article. The article is written in accordance with the guidelines of the scientific journal of BMC Nutrition: [BMC Nutrition | Research article \(biomedcentral.com\)](https://www.biomedcentral.com).

2.0 Introduction

At the turn of the twenty-first century, the prevalence of inflammatory bowel disease (IBD) has increased globally (Hsieh et al., 2020; Ng et al., 2017). IBD is a chronic inflammation of the gastrointestinal tract; the most common forms of IBD are ulcerative colitis (UC) and Crohn's disease (CD) (Selvaratnam et al., 2019). Common symptoms of both UC and CD are abdominal pain, rectal bleeding, diarrhoea, fatigue, reduced appetite and unintended weight loss (Falvey et al., 2015; MayoClinic, 2021). According to an review article from 2020 (Ananthakrishnan et al., 2020) IBD affects 3.2 million people in Europe. In Norway the prevalence has also increased; approximately 0,80% of the population in Norway have the disease (ibd.as). Annually, 250 people get diagnosed with CD and 600 with UC (ibd.as).

Malnutrition is a common problem for both UC and CD patients; but CD patients are considered to be more affected because CD affects any part of the gastrointestinal tract, UC is restricted to the colon (Forbes et al., 2017; Stoner et al., 2018). One of the most common types of malnutrition in IBD is micronutrient deficiencies or lack of or low levels of important vitamins and minerals (Balestrieri et al., 2020). The most common deficiencies are iron, vitamin D, vitamin B12, zinc, and folic acid deficiency (Schreiner et al., 2020).

The most important factor associated with malnutrition in IBD is inadequate dietary intake, related to avoidance due to worsening of symptoms (abdominal pain, nausea, diarrhoea) after eating or loss of appetite (Marcil et al., 2019; Pulley et al., 2020). Malabsorption and side effects of medication also contribute to increased risk of developing malnutrition (Balestrieri

et al., 2020; Pulley et al., 2020; Scaldaferrri et al., 2017). Malnutrition can also be a result of surgery (Balestrieri et al., 2020).

A Dutch self-administered online questionnaire assessing the dietary beliefs, dietary behaviours and nutritional knowledge among 294 IBD exposed that majority (76,5%) favoured avoided certain foods over following a certain diet or eating more beneficial foods (57%) to avoid disease symptoms. The most common avoided foods were spicy foods, seasoned foods, milk and other dairy products and carbonated drinks (de Vries et al., 2019). Several other studies (Casanova et al., 2017; Shafiee et al., 2020; Tomar et al., 2017) also showed that majority of IBD patients did practice food avoidance.

Malabsorption and side effects of medication also contribute to increased risk of developing malnutrition (Balestrieri et al., 2020; Pulley et al., 2020; Scaldaferrri et al., 2017).

Malabsorption is caused by the inflammation of the intestines and makes it difficult to absorb necessary nutrients in the small intestine. The degree of malabsorption depends on how much of the small intestine is affected; if larger parts of the small intestine are inflamed or they have been surgically removed the malabsorption often is more significant (Crohn's&colitisfoundation, 2021). Certain medications, common in IBD treatment contribute to malabsorption (Dubois-Camacho et al., 2017; Nemeş et al., 2016; Scaldaferrri et al., 2017). Exogenous glucocorticoids (GCs) are widely used as anti-inflammatory therapy in IBD (Dubois-Camacho et al., 2017). GCs can interfere with the absorption and utilization of zinc, calcium and phosphorus. Long exposure to GCs is associated with osteoporosis and bone alteration(Scaldaferrri et al., 2017). Drug likes Sulfasalazine and cholestyramine can impair the absorption of folate acid, iron, fat-soluble vitamins, iron and B12; contributing to heighten risk of anemia, hyperhomocysteinemia (high levels of the amino acid homocysteine; can contribute to blood clots and arterial damage) and steatorrhea (fatty stool) (Healthline, 2018; Nemeş et al., 2016; Scaldaferrri et al., 2017).

Follow-up and treatment of IBD patients varies in different countries (Lirhus et al., 2021). In Norway, people with IBD are followed-up and treated in outpatient clinics by a specialist or nurse (LMF; Olbjørn, 2017). Patients also need to be followed-up by their general practitioner (LovisenbergDiakonaesykehus, 2020). The treatment of IBD usually includes drug therapy or surgery (Mayoclinic, 2021), but diet therapies along with dietary guidance

has become an important pillar in the treatment of IBD (Durchschein et al., 2016; Green et al., 2019).

Diet therapy can be defined as the practical application of nutrition either as preventative treatment or as a cure (Nutrition&dietics, 2020). Malnutrition in IBD can be corrected and symptoms can improve through diet therapy (Yoon, 2019). Traditionally, diet therapy has been considered a complementary therapeutic option, but now nutrition is also suggested as a primary treatment to induce or maintain remission (Durchschein et al., 2016). Many studies have shown that clinical remission in IBD can be achieved with different nutritional regimes (Durchschein et al., 2016). There have been several studies on the effect on FODMAP (fermentable oligosaccharides, disaccharides, monosaccharides, and polyols) reduced diet, CD exclusion diet, specific carbohydrates diets and IBD (Durchschein et al., 2016; Rummelle, 2016).

The FODMAPs diet is often used to manage gastrointestinal symptoms for patients with irritable bowel syndrome (IBS), but some studies show that the diet can reduce IBS-like symptoms in IBD patients (Cox et al., 2020; Gibson, 2017; Zhan et al., 2018). Some studies show that the diet can reduce gastrointestinal symptoms such as abdominal pain, abdominal distension, stool frequency and consistency in IBD patients (Böhn et al., 2015; Milajerdi et al., 2020; Pedersen et al., 2017; Zhan et al., 2018). The Crohn's disease exclusion diet (CDED) and the Specific carbohydrate diet (SCD) can induce remission and improve clinical outcomes in paediatric and adult patients with IBD (Burgis et al., 2016; Cucinotta et al., 2021; Levine et al., 2019; Obih et al., 2016; Sigall Boneh et al., 2017).

There is an increased interest in dietary guidance among patients and within the research community in Norway (Knudsen & Lorentsen, 2020). In a study conducted by the Norwegian national association against digestive disease (LMF) in 2019, among their members, 87,3% had tried modifying their diet, despite the fact that they were often told diet is not connected to the disease. Members also reported wanting dietary guidance and 96% wanted further research on IBD and diet (Knudsen & Lorentsen, 2020).

Even though there is an increased interest in dietary guidance among IBD patients (Knudsen & Lorentsen, 2020), we know little about how they experience dietary guidance and if

they receive sufficient nutritional information from healthcare providers during their follow-ups. Dietary guidance is little integrated in the treatment of IBD in Norway because diet, and its importance, has not received a lot of attention (Knudsen & Lorentsen, 2020).

IBD patients are generally interested in modifying their diet and many believe diet and nutrition impact their disease (Gu & Feagins, 2019; Nazarenkov et al., 2019). Studies have shown that it is common for IBD patients to modify their diet based on their beliefs and the course of their disease (Bach et al., 2014; Crooks et al., 2021; de Vries et al., 2019; Marsh et al., 2019; Nowlin et al., 2021). Supplementation, food avoidance or restrictions and following a specific diet are some of the most common dietary adaptations (Bach et al., 2014; de Vries et al., 2019; Marsh et al., 2019).

There are some general dietary guidelines and recommendations for IBD patients (Forbes et al., 2017; Levine et al., 2019). The ESPEN guideline is based on extensive systematic review and presents a multidisciplinary focus on clinical nutrition in IBD (Forbes et al., 2017). The guidelines described 40 recommendations related to nutrition, malnutrition, physical activity and pregnancies in IBD. Recommendation 5A, 28 and 29 are some of the recommendations regarding nutrition: Recommendation 5A - during active disease the protein intake should increase (to 1.2-1.5 g/kg/d in adults) relative to the general recommendation for the general population. Recommendation 28 - all IBD patients in remission should undergo counselling by a dietitian as a part of a multidisciplinary approach to improve nutritional therapy and avoid malnutrition and nutrition-related disorders. Recommendation 29 states that there is not one specific diet that should be followed during the remission phase in IBD; general advice on health eating can be given to both patients with UC and CD. To our knowledge, ESPEN guidelines are not used during the treatment or subsequent follow-up of IBD patients in Norway.

The international organization for the study of inflammatory bowel disease developed some dietary guidelines based on the best current available evidence in regard to specific dietary components, food groups and food additives (Levine et al., 2019). The key recommendations for UC were reduced consumption of red meat and myristic acid (palm oil, coconut oil, dairy fats) and increased consumption of omega-3 fatty acid, but not from supplements. CD patients were recommended to increase the consumption of fruit and vegetables and restrict the intake of insoluble fibre and saturated fats. Reducing the intake of emulsifiers and

thickeners, processed foods with titanium dioxide and sulfites, trans fat, artificial sweeteners and unpasteurized dietary products were recommended for both CD and UC (Levine et al., 2019).

Dietary guidance should be a part of a multidisciplinary approach to the treatment of IBD (Forbes et al., 2017). Dietary modification and malnutrition are common among IBD patients (Gu & Feagins, 2019; Nazarenkov et al., 2019); tailored dietary guidance from a trained dietitian or healthcare provider with expertise in nutrition will ensure patients an adequate nutrients intake and subsequently avoid malnutrition (Shafiee et al., 2020).

Studies on how patients experience to receive dietary guidance are sparse. Some studies show that majority do not receive dietary guidance despite the fact that majority consider it to be important (Bernstein et al., 2011; Holt et al., 2017; Limdi et al., 2015; Wong et al., 2012). No qualitative study has been conducted in Norway. A qualitative study that highlights this topic can provide valuable details about how patients with IBD communicate with their healthcare providers, and hopefully contribute to a better understanding of patients' needs and preferences in regard to dietary guidance.

3.0 Aim of the study

The purpose of this study was to explore how patients with IBD experience dietary guidance.

4.0 Theoretical framework

4.1 Nutrition communication

Patients with IBD may benefit from evidence- and theory-based nutrition communication strategies. Nutrition communication can be considered as a specific and important sub-area within health communication (Holli et al., 2009). Ishikawa & Kiuchi (2010) defines health communication as interpersonal, or mass communication activities focused on improving health and preventing disease of individuals and populations (Ishikawa & Kiuchi, 2010). The main goal of health communication is to promote changes in health-related behaviour, patient adherence, self-management, disease control; and sustain and adopt beneficial health policies

and practices to improve public, community and individual health outcomes (Bukstein, 2016; Garnweidner-Holme, 2019; Schiavo, 2011).

Nutrition communication can be defined as the process where an individual is informed about nutrition in a way that can be translated into dietary changes (Rayner, 2003). Nutrition communication can occur between health professionals and patients; the health professionals should provide effective health promoting advice about nutrition (van Dillen et al., 2006). A suggested definition for nutrition communication is “the study and appliance of communication strategies informing about a healthy diet on an individual and societal level”. The specific goal of nutrition communication is to increase the population's awareness, attitude, knowledge, preference around food, diet and nutrition” (Garnweidner-Holme, 2019). One of the most individually tailored form of nutrition communication is personal one-to-one dietary guidance (Garnweidner-Holme, 2019).

5.0 Tailored dietary guidance

Individually tailored dietary guidance is meant to help individuals select health-promoting diets; as well as guiding and motoring individuals through different diet therapies (Nutrition&dietics, 2020; Yngve & Tseng, 2010). Studies giving insight into the effects of dietary guidance on IBD patients are scarce, but several studies have researched how tailored dietary guidance affects IBS patients (Mazzawi & El-Salhy, 2017; Mazzawi et al., 2013; Østgaard et al., 2012). As many IBD patients are interested in dietary guidance (Schreiner et al., 2020) and IBS-like symptoms are not uncommon in IBD patients (Gibson, 2017; Tuck & Vanner, 2018) the findings of these studies might also be relevant for IBD patients.

Dietary guidance should be performed by a healthcare provider with expertise in nutrition (Helsedirektoratet, 2018; Mazzawi & El-Salhy, 2017). IBD is heterogeneous: people react differently to different foods and also have varied preferences (Owczarek et al., 2016; Tindemans et al., 2020). Many patients would want individualized dietary guidance that takes their needs and concerns into consideration (Prince et al., 2015). Studies show that tailored dietary guidance can increase confidence and reassurance in patients, ensure adequate nutritional intake, and help patients figure out what food triggers symptoms in IBS patients (Mazzawi & El-Salhy, 2017; Mazzawi et al., 2013; Østgaard et al., 2012). According to a

Norwegian review tailored dietary guidance helps patients with IBS to reduce symptoms, improve quality of life and prevent multiple nutritional deficiencies (Mazzawi & El-Salhy, 2017).

Mazzawi et al., (2013) investigated the impact of dietary guidance on symptoms, quality of life and diary habits in 46 patients with IBS. Out of the 46 patients, 17 completed the entire study and each received individual dietary guidance over a 3–9-month period. The results showed that quality of life increased significantly, and symptoms decreased after dietary guidance. Tailored dietary guidance also seems to be a cost-effective option for disease management in IBS (Mazzawi et al., 2013). Østgaard et al., (2012) wanted to assess how dietary guidance effects changes in food intake, quality of life and symptoms among 114 participants (35 health controls, 79 had IBS) where 43 IBD patients had received dietary guidance 2 years prior. Dietary guidance improved quality of life, symptoms and choice of a healthier diet among the patients that had received dietary guidance (Østgaard et al., 2012).

6.0 Barriers to nutrition communication

Potential risk factors or barriers to nutrition communication, such as limited health literacy, time and communications skills, can also be barrier for providing dietary guidance (Damas et al., 2019; Nutbeam et al., 2017; Ratanawongsa et al., 2021; White et al., 2015).

6.1 Health literacy

Health literacy (HL) describes a person's skills that enables them to obtain, understand and use information when making decisions that will impact their health status (Nutbeam et al., 2017). The level of someone's HL impacts their ability to read and understand forms and medication instructions, seeking out appropriate care for worsening symptoms, navigation of the healthcare system and act on recommendations for prevention and self-care (Tormey et al., 2015). Low HL has been associated with poor overall health outcomes, disease management difficulties, more hospitalizations and decreased medicine adherence among IBD patients (Berkman et al., 2011; Miller, 2016; Tormey et al., 2015).

Screening of IBD patients' HL early in their treatment is necessary to provide better service (Dos Santos Marques et al., 2020). After assessing the patient's HL levels, the

communication should be adapted to meet the literacy level to improve delivery of health information (Davis et al., 2017). There are some studies (Dos Santos Marques et al., 2020; Tormey et al., 2018) that have investigated health literacy levels among IBD patients. However, as far as we aware, there are no studies that have researched this among IBD patients in Norway.

6.2 Time during consultations

Time scarcity during consultations is a barrier to nutrition communication (Tinsley et al., 2016; Whitaker et al., 2016; Wynn et al., 2010). Limited time for each patient affects their ability to provide sufficient dietary guidance (Damas et al., 2019); patients usually have more than one medical issue, so healthcare providers priorities the topics they believe are the most critical or important to cover (Whitaker et al., 2016). As health care providers usually have many patients, limited amount of time with each patients can be a barrier for nutrition communication (Kolasa & Rickett, 2010).

6.3 Patient-provider communication

Both low HL and time scarcity can lead to ineffective communication between patients and healthcare providers can thus, be a in itself barrier to nutrition communication (White et al., 2015). Compared to effective patient-provider communication, ineffective communication does not encourage good relationships between patient and provider or open communication; providers that do not communicate well with their patients don't recognize the patients' needs or include them in the treatment decision-making process (Brinkman et al., 2007; Ha & Longnecker, 2010; Herndon & Pollick, 2002). Communication challenges can contribute to lack of nutrition communication as the practitioner might not consider their patients' needs or won't discuss treatment plans with the patient despite the patient wanting dietary guidance (Khan et al., 2016). Effective communication is important as patients that don't feel their preferences or information need are covered by their healthcare provider, they seek out non-medical advice online (Solomon et al., 2020).

7.0 Multidisciplinary care

Multidisciplinary care might help with barriers in nutrition communication. With a multidisciplinary approach, various specialized healthcare providers cooperate with the

overarching goal of improving treatment efficiency and patient care (Taberna et al., 2020). Treatment of patients with IBD requires a multidisciplinary approach (Malter et al., 2020); multidisciplinary care appears to improve quality of care and support in IBD patients and their families (Ghosh, 2013; Ricci et al., 2008).

IBD does not only affect the gastrointestinal tract, but it also affects the skin, eyes and joints. Additionally, various drugs, as well as inadequate nutritional intake can lead to complications such as infertility, mental illness, opportunistic infections and osteopenia (Koltun, 2017). Therefore, in addition to gastroenterologists and GP, treatment and follow-up of IBD patients should be performed by dietitians/nutritionists, psychotherapists, dermatologists, pathologists, rheumatologists and other healthcare specialists (Ghosh, 2013; Koltun, 2017).

322 patients with IBD were enrolled in a IBD specialty medical home (SMH) (healthcare model with multidisciplinary team and specialists) for one year in a retrospective analysis (Regueiro et al., 2018). The aim of the study was to investigate the effects of SMH on disease activity, quality of life and healthcare utilization. The multidisciplinary care team consisted of dietitian, schedulers, nurse coordinators, social worker, gastroenterologist, psychiatrist and advanced practice providers. IBD SMH seemed to reduce unplanned care (7.3% reduction in emergency department visits and 35,9% reduction in hospitalization), disease activity and an increase in quality of life 1 year after enrolment (Regueiro et al., 2018). There are very few studies that have researched how healthcare provider cooperate during follow-ups of IBD patients in Norway. However, Knudsen & Lorentsen (2020) stated that IBD patients are a vulnerable group that needs to be followed up by a dedicated multidisciplinary care team (Knudsen & Lorentsen, 2020).

8.0 Nutritional information sources - needs and preferences

Many IBD seek nutritional information online (Schreiner et al., 2020; Solomon et al., 2020). Additionally, patients often receive nutritional information from their doctors, nurses, dietitians, and the internet (Crooks et al., 2021; Prince et al., 2011; Prince et al., 2015;

Tinsley et al., 2016; Walton & Alaunyte, 2014). The different sources and information can act as barriers to nutrition communication as they may contain divergent advice.

An English face-to-face survey wanted to assess the opinions of 72 IBD patients and 100 healthcare providers at a gastroenterology outpatient centre regarding the type and quality of written information on nutrition and diet (Prince et al., 2015). 82% had discussed problems related to food and nutrition with a healthcare provider (doctor or nurse) and 2-22% had discussed this with a dietitian. Almost half (47%) had sought out dietary guidance from a dietitian specifically for their IBD. Further, 33% were interested in group sessions where the focus was food and nutrition and 3 patients commented they would use internet forums for information exchanges (Prince et al., 2015).

Walton & Alaunyte (2014) performed an online questionnaire among 93 IBD patients with the aim of assessing professional dietary guidance among others. The majority (56%) reported dietitians, official websites and books as sources for nutritional information (Walton & Alaunyte, 2014).

Prince et al., (2011) invited 87 IBD patients to take part in face-to-face questionnaire interviews where they were asked about nutrition, most significant nutritional problems and to what extent these problems have been addressed by health professionals. The findings showed that almost half (47%) had seen a dietitian for their IBD. There was an interest in attending support groups where they discuss nutrition if it was offered as a part of their treatment in 33% of patients (Prince et al., 2011). Personal experiences, healthcare professionals and the internet (90%, 19% and 11% respectively) were the most common source for nutritional information according to (Crooks et al., 2021). In the American study of (Tinsley et al., 2016) gastroenterologist, dietitians, other physicians, nurses or Nurse practitioners (58.9%, 11.6%, 7% and 3.9% respectively) were identified as the providers they talked about nutrition with (Tinsley et al., 2016).

9.0 Method

9.1 Choice of methodology

In this thesis, qualitative individual interviews were conducted to get a better insight into how patients with IBD experience the dietary guidance they received from health professionals.

A qualitative approach was chosen as we wanted to investigate patients' experiences that have not been well documented before (Thagaard, 2018). Qualitative approaches are well suited when we want to understand situations from the point of view of those involved (Britten, 2011, p.385). In addition, individual interviews were chosen because the participants have the opportunity to explain how they experience their situation (Thagaard, 2018).

The use of qualitative interviews was well suited for our study as there are no studies in Norway that have researched how patients with IBD experienced receiving dietary guidance. These interviews provided us with in-depth data about the participants' experiences which we would have not been able to obtain by quantitative approaches (Dalland, 2012). A quantitative approach, such as a questionnaire, would not have been well suited for our study as we were not interested in gaining information about how many had discussed nutrition with their healthcare provider, but rather how the experiences of receiving dietary guidance felt like to the participants (Dalland, 2012).

9.2 Interviewing

The recruitment of participants was performed through purposive sampling by the project leader and myself. This implied that participants were chosen based on the characteristics relevant to the research questions (Thagaard, 2018): being between 18-50 years old and being diagnosed with IBD for at least 6 months. Late in the recruitment process, the age limit was increased to include patients up to 60 years old. The project leader had to send an e-mail (see appendix 1) to the Norwegian centre for research data (NSD) asking for permission to include participants over 50 in the study. This was necessary as the project leader had to recruit participants for three master theses, and therefore, there was a shortage of participants. In addition, several people above the age of 50 years wanted to participate in the study

An invitation to participate in the study was published on the website of the Norwegian national association against digestive disease (LMF). People who were interested in participating as well as having the right characteristics were recruited by the project leader. The contact information of the first recruited participant was forwarded by the project leader to my supervisor, who scheduled the pilot interview. For the rest of the interviews, the contact information of the recruited participants was directly forwarded to me; I subsequently contacted the participants to schedule interviews. Because of the Covid-19 pandemic 5 out of 10 interviews were held over the telephone.

The interview guide (see appendix 2) was developed by the project group which consisted of the project leader (senior lecturer in nursing), my supervisor (associate professor in public health nutrition), and my co-supervisor (associate professor in physiotherapy). During the writing of the thesis, I had discussions with and received feedback from all three of them about the interviews, transcription and analysis process.

The interview guide focused on four topics: 1. Experiences with receiving advice about nutrition from an interdisciplinary health professional team, 2. Experiences with receiving advice about physical activity from an interdisciplinary health professional team, 3. Experiences and attitudes towards integrative healthcare, 4. Interdisciplinary collaboration between health personnel.

The interview guide was semi-structured. Semi-structured interviews gave us the opportunity to adjust our questions based on the participants' answers and include questions that were not a part of the interview guide (Thagaard, 2018). Furthermore, it gave the participants the chance to talk about topics that concerned them and simultaneously answered the question we wanted them to answer (Thagaard, 2018).

A pilot interview was conducted by me and my supervisor to test how well the interview guide worked in meeting with a potential participant. The pilot interview led to minor changes in the interview guide such as change of wording by the project leader (see appendix 3). Some questions were re-worded to be more open, e.g., the question "Is it important for you to eat healthy?" was changed to "What are your experiences with food?". Questions under theme 4 were also changed to be more open. The question "How do you experience cooperation between other health personnel?", was replaced by questions about how the

participants believed the healthcare system could be improved. By changing the question “is it important for you to eat healthy?” we gave the opportunity for the second interviewee to present their views and experiences around food (Thagaard, 2018). The question could have been considered a leading question by the participants as it limited the ways she could respond. In addition, it might have made her feel like she had to agree or disagree with me (considering I’m a public health nutrition student) (Thagaard, 2018). Therefore, the pilot interview was included in the data material.

I interviewed 11 people, but one interview was lost because of a problem with the recording device. Therefore, data from 10 interviews are included in the study. Each interview lasted between 15 and 50 minutes. The participants chose their preferred places to be interviewed and 5 were interviewed over the telephone. Of the remaining interviews, 4 were conducted at one of Oslo Metropolitan university’s (OsloMet) campuses and 1 at the interviewee’s home. The interviews were conducted and transcribed during the period October 2020-December 2020.

9.3 Analysis and transcription

The interviews were recorded using the recording app “Nettskjema-dictaphone” without network connection. Nettskjema-dictaphone is an approved-recording equipment and in accordance with OsloMets’ guidelines for data security and privacy. I transcribed the audio files verbatim on a computer without internet connection.

The thematic analysis used in this thesis is based on Braun and Clarke (2006) ’s six step framework for data analysis. Braun & Clark (2006) describes thematic analysis as a method for identifying, analysing, and reporting patterns (themes) within data. Thematic analysis is not grounded in a pre-existing theoretical or epistemological position and therefore differs from other qualitative analytic methods e.g., ground theory or narrative analysis (Braun & Clarke, 2006).

The goal of a thematic analysis is to identify themes or patterns in the data that can say something about the issue being studied (Maguire & Delahunt, 2017). When analysing the data, we used an inductive approach. With an inductive approach we coded part of the data

that were of interest. This data was later refined into subthemes and then main themes (Braun & Clarke, 2006).

The analysis was carried out as follows:

1. Familiarizing myself with the data

I started familiarizing myself with the data when I conducted the interviews. This implied that I listened to the interviews thoroughly. I transcribed on a computer without internet connection. In addition, the transcripts were read and re-read by both me and my supervisor.

2. Generating initial codes

After the interviews were transcribed, I read through them and had thoughts and ideas for potential codes. (Braun & Clarke, 2006), through Boyatzis (1998), describes codes as the most basic segment, or element, of the raw data or information that is of interest and may be interesting in regard to the research question (Braun & Clarke, 2006). With the help of NVivo12 I coded part of the data I found interesting in regard to the research question and labelled them. Later, my supervisor and I looked through the codes and discharged the codes that were not relevant to the research question.

3. Searching for sub-themes

At this stage, I started to create sub-themes. Codes that were similar and connected were put in the same sub-themes.

4. Reviewing sub-themes

Next, my supervisor and I reviewed the sub-themes. We assessed the sub-themes and discussed whether they represented the data accurately. Further, we discussed the relevance of the sub-themes in terms of the research question. Some sub-themes were combined, or new ones were created. The sub-themes that were not relevant to the research question were discharged.

5. Defining and naming themes

In this step, related sub-themes were merged into main themes. Main themes were further defined and named. An example of labelling codes and arranging them in sub-themes and main themes is shown in Table 1.

6. Reporting the results

Finally, I wrote the results of this analysis in the result section of the attached article. The most relevant themes were presented, and the use of quotes from the participants were used to support my statements of these themes. I arrived at 3 themes total and 13 sub-themes. The results will be described in detail in chapter 11.

Table 1. Example of how codes are put into sub-themes and main themes

Text in the transcript	Codes	Sub-theme	Main theme
“But I have received very little advice regarding diet generally, from both doctors and clinical dietitians, yes, I have had to fight through by myself” “In the beginning, I was told “No, it varies what people can eat and can’t eat. So, you just have to figure it out by yourself”	Have received very little dietary guidance from healthcare professional during their follow-ups	Rarely or never talk about nutrition with healthcare professionals	More need for dietary guidance

9.4 Validity and reliability

To consider the credibility of a scientific study we need to consider its validity and reliability (Thagaard, 2018). Thagaard (2018) states that the validity of a study is connected to the results of the study and how we interpret it (Thagaard, 2018). Thagaard (2018) states that validity is a question about if our interpretation of our findings is valid; set up against the reality we are searching (Thagaard, 2018). Validity can be described as internal validity and external validity. When discussing internal validity, we address how well the participants' responses fit with the researcher representation of them (Tobin & Begley, 2004). External

validity refers to the generalizability of the study, how well the findings fit in other contexts (Tobin & Begley, 2004).

When discussing reliability, we need to explain how we developed the data and how our experiences as a researcher affected the development of the data (Thagaard, 2018). Reliability can also be described as internal and external reliability. Internal reliability includes the consistency with data collecting, analysing and interpreting the data; would another researcher obtain the same results using the same analysis as the original researcher? (Zohrabi, 2013). External reliability is concerned about the replicability of the study; to what degree an independent researcher would reproduce similar findings in the same study (Zohrabi, 2013). I will discuss how I ensured validity and reliability in my research in chapter 11.

9.5 Ethical considerations

This study was approved by the Norwegian Centre for Research Data (NSD; Nr 697660, see appendix 4). The study was conducted in accordance with OsloMets ethical research guidelines and NSDs private policy. The participants were assured confidentiality and were told they could withdraw from the study at any time without giving a reason. Prior to the interviews participants had to either sign a written consent (see appendix 5) form or send an email (in the case of phone interviews) where they consented to participation.

10.0 Summary of results

This study investigated how patients with IBD experience dietary guidance. Three main themes were identified: 1) More need for dietary guidance, 2) Experiences of dietary guidance from clinical dietitians and 3) experiences with dietary guidance from other health professionals. I will discuss the results in chapter 12.

More need for dietary guidance

Most patients expressed a need for more dietary guidance. Many patients wanted to make dietary changes as they believed it would alleviate symptoms. Some patients were given small pieces of advice about nutrition from their GP or gastroenterologist but were not provided any tailored advice. Some patients felt, or got the impression, that the level of knowledge about what patients with IBD should be eating was very low among the healthcare

providers involved in their care. Generally, participants were often advised by their GP or gastroenterologist to figure things out for themselves. Most patients felt like they had to take a lot of personal responsibility to get the information about nutrition they wanted or needed. Therefore, the majority sought support and information from the internet.

Experiences of dietary guidance from clinical dietitians

The participants' encounter with a clinical dietitian was described as both useful and unhelpful. Some patients appreciated being followed up by a clinical dietitian. Several patients felt the clinical dietitian did not have sufficient knowledge about IBD-nutrition. Several participants found it difficult to get a referral to a clinical dietitian. One patient wanted contact with a dietitian early on in their treatment but had to convince their gastroenterologist to get a referral.

Experiences with dietary guidance from other health professions

For the majority, nutrition was generally very little talked about. Dietary guidance was provided to several participants, but many did not find it adequate as it usually was not tailored to them. If a patient received dietary guidance by a gastroenterologist or GP, they were usually advised to avoid certain foods. Some patients believed their gastroenterologist had a negative attitude towards diet as a part of their treatment.

11.0 Methodological discussion

11.1 Individual interviews

As far as I am aware, this study is the first study to qualitatively explore how patients with IBD experience dietary guidance in Norway. There are some studies that have researched nutrition in IBD (Skrautvol & Nåden, 2011, 2015) in Norway, however, these studies do not research dietary guidance among IBD patients.

Individual interviews gave the participants the opportunity to elaborate their answers. This gave me good insight and understanding of how they felt and thought about nutrition as a part of their treatment, their encounters with health personnel, and to which degree nutrition was

talked about during treatment and follow-ups. The interviews were semi-structured and gave me the opportunity to ask additional questions, elaborate myself or ask them to elaborate on certain topics or questions. Semi-structured interviews allowed me to pay attention and let the participants talk about what was important to them and also made sure that the themes that were important to the research question were covered (Thagaard, 2018). This approach promoted a two-way-communication and therefore, a more natural setting for the participants to share detailed personal information.

As a result of the Covid-19 pandemic half of the interviews were conducted by telephone. Conducting interview over the telephone was approved by NSD. The participants had the opportunity to choose if they wanted to be interviewed in person or over the telephone. The benefits with telephone interviews were related to flexibility and convenience for both the participants and me as an interviewer. When conducting the telephone interviews, I did not have to think about geographical constraints and time and expenses associated with travel when scheduling interviews as also identified in other studies (Irani, 2019). This allowed me to obtain information from one participant that did not live in the Oslo-Viken area. In addition, in late November there was a shortage of participants to include in the study. This led to the project leader sending an e-mail to NSD requesting to include participants that were older than the original age criteria (maximum 50 years). As a result of this, I could not interview more participants for some 2-3 weeks. Telephone interviews allowed me to make up the lost time, as I could fit 2-3 interviews in one week.

Telephone interviews allows the participants to choose their location during their interview, not least the opportunity to be interviewed in their own home. Being interviewed in a familiar and comfortable setting promotes openness, which is especially important when talking about very personal experiences (Drabble et al., 2016). The biggest challenge I experienced with these types of interviews was the lack of nonverbal communication. Unlike face-to-face interviews, I didn't get feedback through body language and facial expressions. This made it more difficult in terms of both the interviewing process and the data analysing as I could not use visual cues to aid me in interpreting what was said as also identified in other studies (Carr & Worth, 2001).

11.2 Choice of inclusion criteria

I did not participate in choosing inclusion criteria. However, the project group wanted to include participants who have had IBD for 6 months or longer. The reason they wanted the participants to have had the disease for minimum 6 months was because they would have had more treatment and follow-ups, and subsequently have more information to share in regard to what they were researching.

11.3 Recruitment strategy

A relatively small sampling size is common for smaller qualitative studies (Braun & Clarke, 2013). It was important to choose potential participants with characteristics that were relevant to our research question so that we could gather data that gave us an understanding of the topics we were researching (Thagaard, 2018). According to (Braun & Clarke, 2013) the sample size should be large enough to convincingly demonstrate patterns across a data set, but small enough to retain a focus on the experiences of individual participants. Braun & Clarke (2013) suggests a sample size of 6-10 participants for smaller projects. Our sampling size was 10 participants which was sufficient as we met our saturation point (Braun & Clarke, 2013).

We chose to recruit participants who had been invited through the Norwegian national association against digestive disease (LMF)'s website. This resulted in us making contact with patients with IBD that were either members of LMF or that had visited LMF's website. By cooperating and utilizing LMF's website to come in to contact with potential participants we were able to reach and inform many patients about the project and recruit interested participants with the desired characteristics. Furthermore, by recruiting participants through LMF we recruited participants who were especially interested in information about IBD.

11.4 Analysis

I conducted a six-step thematic analysis of (Braun & Clarke, 2006). As a novice researcher this analysis was a good choice as I did not have a lot of experiences with other qualitative approaches. In addition, the method has few procedures and is not grounded in one specific

theory or epistemological standpoint, which made it an easy method to learn (Braun & Clarke, 2006). As mentioned previously, the interviews were analysed inductively. An inductive approach was used because I did not have a lot of pre-knowledge about the research questions. The analysis through the participants' explanations and thoughts helped me reflect over the reality about dietary guidance in their treatment and follow-ups (Braun & Clarke, 2006). I was able to code and label patterns (themes) that in rich detail described how the participants, on the whole, had experienced receiving dietary guidance (Braun & Clarke, 2006). However, since there is no clear agreement about how you should perform a thematic analysis (Braun & Clarke, 2006), I initially found it difficult to know how to go about it. I found it confusing, especially in the start, as I was unsure about what aspects of the data were interesting or important.

Even though I tried to stay as neutral as possible during the analysing process, I could not completely free myself from my theoretical and epistemological commitments (Braun & Clarke, 2006). My educational background as a Public health nutrition student would have affected the way I both analysed the data and how I performed the interviews. Moreover, with this in the back of my mind I tried to be as neutral as possible during these processes. The method gave me the opportunity to give an interesting and clear description of the data which helped represent the participants' experiences as they described them.

Thematic analysis focuses on themes across interviews rather than what the specific participants say. As a researcher, my understanding and knowledge about the topic I'm studying affected the way I analysed the situation. On the other hand, if some participants share the same opinions or experiences, my description of that reality can cause them to recognise themselves in those results (Thagaard, 2018).

11.5 Ensuring validity and reliability

As described above, for a study to be considered credible the researcher has to ensure validity and reliability of their findings. (Thagaard, 2018), through Marshall & Rossman (2016), stated that we discuss the quality of a study based on its credibility. Both validity and reliability need to be assessed to ensure that the research has been conducted in a believable and reliable way, and to make sure our analysis of the findings are valid (Thagaard, 2018)

11.5.1 Validity

Validity is related to our interpretation of our findings (Thagaard, 2018). To ensure the validity of the findings both my supervisor and I read through and discussed the codes, sub-themes and themes and agreed that they reflected reality. In addition, the findings were read by and discussed with the project leader and the co-supervisor to ensure further validity. Nonetheless, our findings are context specific and can merely be transferable to similar context to that of the participants and cannot be generalized to all patients with IBD in Norway. Another way we strengthen the validity was through using quotations from the participants. Quotations from the participants were translated to English and used to support my findings and therefor highlight that they are grounded in reality. The results of this study are context-specific: they are only transferable to other IBD patients in similar contexts and cannot be generalised to apply to all patients with IBD.

11.5.2 Reliability

The reliability of a study is connected to whether the research has been conducted in a trustworthy and believable way (Thagaard, 2018). To ensure external reliability I tried to describe my research process in detail. Replicability describes to what extent another researcher would get the same results based on the methods I used (Zohrabi, 2013). I strived to describe how the interview guide was developed, how and where participants were recruited, how they were interviewed and my position as a researcher. Further, I tried to thoroughly describe how I analysed the data. Even so, it's hard to know if replicability has been accomplished.

The reason for this is because as a researcher it is hard to be completely neutral as I might have been affected by factors around me. When I interviewed the participants, I aimed to be as neutral as possible. I tried not to ask leading questions, even though I realised I did so in couple of interviews. In addition, the location might have affected the atmosphere and subsequently the way I acted as an interviewer. Compared to the interviews carried out at OsloMets campus; the interviews conducted in the participants homes were more relaxed.

One way I ensured internal reliability was by transcribing the interviews verbatim. By doing this I ensured an accurate description and representation of the participants' experiences. I also tried to produce an accurate report of my research strategy and analysis method which increases transparency and subsequently internal reliability. Further, my supervisor read

through the transcribed interviews to ensure the quality. This might make it easier for others to evaluate the research process step-by step.

12.0 Discussion of the results

Potential barriers for successful dietary guidance for patients with IBD

In our study, patients with IBD experienced that nutrition was rarely talked about in their meetings with gastroenterologists or GPs. Many felt like their healthcare provider did not listen to them or was not interested in providing dietary guidance despite the fact that the majority of the patients felt a need for dietary guidance.

Our findings indicate some barriers for sufficient nutrition communication among patients with IBD and their healthcare providers. As described earlier, nutrition communication is the process where an individual is informed about nutrition in a way that can be translated into dietary changes (Rayner, 2003). One-to-one dietary guidance by healthcare providers with expertise in nutrition is the most tailored form for nutrition communication (Garnweidner-Holme, 2019). As the majority of our participants did not receive dietary guidance, our findings could suggest that nutrition communication was not sufficient.

Participants in our study did not directly talk about perceived barriers to why they did not get dietary guidance, but several patients did mention that they believed their healthcare provider lacked knowledge and interest in IBD-nutrition. Several patients stated that their GP or gastroenterologist did not believe nutrition would help alleviate their symptoms.

Similarly, findings from the American study of Tinsley et al. (2016) found that less than half of the gastroenterologist thought that nutrition was important. Tinsley et al. (2016) wanted to evaluate the knowledge, attitude, and beliefs regarding nutrition in 567 IBD patients and 223 providers. According to Whitaker et al. (2016) healthcare providers usually cover the subject areas they believe to be the most important and therefore, can only cover certain issues because of limited time with patients (Whitaker et al., 2016). Similar findings were presented in other studies (Damas et al., 2019; Kolasa & Rickett, 2010). The review of Damas et al. (2019) wanted to provide clinicians with a summary of the latest evidence behind diets

popular among patients and provide guidance to practitioners among others. According to the review, limited time during consultations can affect the provision of dietary guidance (Damas et al., 2019). Kolasa & Rickett (2010) published a survey of primary care providers; the findings reported that a high number of patients and limited time during consultations is a barrier in regard to the dietary guidance. The findings of these studies (Damas et al., 2019; Kolasa & Rickett, 2010; Whitaker et al., 2016) and our study could indicate that not believing that nutrition was important was potential barriers for providing dietary guidance among healthcare providers. The finding of Damas et al. (2019), Kolasa & Rickett, (2010) and Whitaker et al., (2016) indicated that limited time with each patient could be a barrier for successful dietary guidance. However, as we did research this in our study, we cannot conclude that time scarcity is a barrier.

Some participants in our study believed that their healthcare provider did not have sufficient knowledge about IBD-nutrition. According to a Dutch qualitative study (van Dillen et al., 2006), healthcare providers need to have nutritional knowledge in order to be able to implement nutrition communication strategies such as dietary guidance. This study aimed to identify nutrition communication styles of Dutch GPs, their strategies regarding nutrition communication and nutrition information seeking behaviours. Findings from other studies (Damas et al., 2019; Schreiner et al., 2020; Tinsley et al., 2016) and our study could suggest that a lack of nutritional knowledge might be a contributing barrier for successful nutrition communication.

According to Damas et al. (2019) lack of nutrition knowledge as well as limited available guidelines based on prospective data, are some of the primary factors contributing to lack of dietary guidance (Damas et al., 2019). Similar findings were found in other studies (Schreiner et al., 2020; Tinsley et al., 2016; van Dillen et al., 2006). Results from Tinsley et al. (2016) showed that providers reported not receiving adequate education about IBD-nutrition in their training and therefore only being comfortable giving basic recommendations (Tinsley et al., 2016). Less than half felt they had adequate nutritional care resources to initiate and provide dietary guidance. Similarly, in the study of van Dillen et al. (2006) some GPs reported feeling that their own nutritional knowledge was insufficient, and a majority reported referring their patients to a dietitian (van Dillen et al., 2006).

A Swiss review summarized the current knowledge and recent data on IBD and nutrition and discussed how to best recognize, treat and prevent nutrient deficiencies in IBD patients among others (Schreiner et al., 2020). According to Schreiner et al. (2020) the reason why physicians are reluctant to provide dietary guidance is because there is a lack of robust evidence on specific diets. Schreiner et al. (2019) also stated that even though there are no specific dietary recommendations for IBD patients, it's crucial that they provide some dietary guidance and encourage a healthy and balanced diet based. This might also be the case in our study; there might be a lack of available and specific dietary recommendations for IBD patients in Norway, contributing to the lack of IBD-specific dietary guidance by healthcare providers.

In contrast, the American study of Malter et al. (2020) found that 72% out of 197 healthcare providers who worked with IBD patients reported being comfortable making dietary recommendations. The study was a prospective web-based survey aiming to describe the self-identified IBD knowledge and resource gaps of clinicians in order to inform the development of future programming (Malter et al., 2020).

In our study, many patients were currently adapting their diet or had made dietary adaptations. In addition, several of these patients reported using sources such as the internet to obtain nutritional information. These findings could have indicated that participants generally knew where to obtain nutritional information and how to implement this into their diet. The majority of the participants also sought dietary guidance from their GP or gastroenterologist which suggested they knew where to get dietary guidance. Additionally, when they did not receive adequate dietary guidance, they sought nutritional information elsewhere. In accordance with Solomon et al. (2020) IBD patients who do not feel their information needs are met, usually seek information online. Knowing where to find and how to use nutritional information is related to person's health literacy levels (Nutbeam et al., 2017). Our findings might indicate that the participants in our study knew where to get dietary guidance and how to implement it into their diet. However, as we did not assess the participants health literacy, we cannot conclude that they had adequate health literacy levels to critically access the information they have found by themselves.

Our findings and the findings of studies (Damas et al., 2019; Schreiner et al., 2020; Tinsley et al., 2016) might indicate that lack of interest in nutrition could be a barrier. Providers might

not be confident in providing dietary guidance as they do not feel they have sufficient nutritional knowledge. In addition, nutrition communication also includes restricting misinformation about nutrition (Rayner, 2003); healthcare providers might shy away from dietary guidance as they do not want to give advice about topics, they aren't experts in. However, since we did not perform a knowledge study among healthcare providers, we cannot conclude that the lack of dietary guidance is caused by insufficient nutritional knowledge.

Need for individually tailored dietary guidance

In our study, patients asked for dietary guidance based on their individual experiences and needs. However, the majority were just told to avoid certain food groups since some former patients had reacted to these rather than receiving tailored advice. Many wanted dietary guidance as they believed it could help with symptoms.

Individually tailored dietary guidance should be included in IBD treatment to improve treatment satisfaction and prevent nutritional deficiencies (Mazzawi & El-Salhy, 2017; Mazzawi et al., 2013; Solomon et al., 2020); it would take the patient's diet, preference, challenges and knowledge into consideration when discussing food and nutrition (Garnweidner-Holme, 2019). According to the review of Solomon et al., the lack of support and guidance from a healthcare provider when practicing dietary adaptations increases the chance of nutritional deficiencies and worsening disease state in IBD patients (Solomon et al., 2020). The review provided an overview of dietary treatment options, the current knowledge about patient motivations for pursuing dietary therapy, and the roles of patient empowerment and patient activation (Solomon et al., 2020).

The Norwegian review of (Mazzawi & El-Salhy, 2017) reported the provision of dietary guidance as a first-line treatment for managing IBS among others. As mentioned previously, since IBS-like symptoms among IBD patients are not uncommon (Gibson, 2017; Tuck & Vanner, 2018), findings from studies looking into the effects of dietary guidance on IBS patients might be relevant for IBD patients. According to the review individual dietary guidance helps patients with IBS to avoid multiple nutritional deficiencies, reduce symptoms and improve quality of life (Mazzawi & El-Salhy, 2017). Another Norwegian study (Østgaard et al., 2012) wanted to assess how dietary guidance effected changes in food intake, quality of life and symptoms among 114 participants (35 health controls, 79 had IBD).

43 of the IBD patients had received dietary guidance 2 years prior. Results showed that dietary guidance improved quality of life, symptoms and choice of a healthier diet among the patients that had received dietary guidance.

Just like the disease, IBD patients are a heterogeneous group: people react differently to different foods, have varied preferences and level of nutritional knowledge (Owczarek et al., 2016; Tindemans et al., 2020). To be able to provide adequate individual tailored dietary guidance the patients' health literacy should be taken into account when performing dietary guidance (Davis et al., 2017). A patient with low health literacy would not be able to fully understand and use the nutritional information they would get through dietary guidance even if it was tailored to them (Miller, 2016; Nutbeam et al., 2017; Tormey et al., 2015). After assessing the patients' health literacy levels, the communication should be adapted to meet the literacy level to improve delivery of health information (Davis et al., 2017).

These findings seem to indicate that individualized dietary guidance can contribute to prevention of nutritional deficiencies in patients who adapt their diet. Furthermore, to provide adequate dietary guidance healthcare providers should assess their patients' health literacy and adapt their information accordingly.

In conclusion, this study indicated that dietary guidance is a major need for patients with IBD. Many patients felt they were left to themselves and were not supported when it comes do dietary changes. The patients encounter different healthcare providers but receive inadequate dietary guidance; and subsequently seek nutritional information and support elsewhere. In meeting with patients with IBD, healthcare providers should get more motivated and get more knowledge to provide dietary guidance related to IBD.

13.0 References

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14.0 The article

Title: Experiences with dietary guidance among patients with Inflammatory Bowel Disease - A qualitative study

To be submitted to: BMC nutrition

Key point

Current awareness: Dietary guidance is an important pillar in the treatment of IBD. Studies that research how IBD experience dietary guidance is sparse. There is no study investigating this in Norway.

Main statement:

- There was a great interest in dietary guidance among the IBD patients, but many do not receive it
- Patients met various healthcare professionals during follow-up, sometimes dietitians
- Many patients experienced that healthcare providers had little knowledge about IBD-nutrition, including the dietitians
- Many felt like they were left to themselves and sought information from other sources than healthcare providers
- Based on our findings, dietitians and other healthcare providers with expertise in nutrition should be more involved in the follow-up of IBD patients

Experiences with dietary guidance among patients with Inflammatory Bowel Disease - A qualitative study

Abstract

Background: The prevalence of Inflammatory Bowel Disease (IBD) increases rapidly worldwide. Dietary guidance is an important pillar in the follow-up of patients with IBD. To provide patients with efficient dietary guidance, we need more knowledge about how they experience dietary guidance. This study explores how patients with IBD experience dietary guidance provided by different health professionals.

Methods: Semi-structured, individual interviews were conducted with 10 patients (1 male, 9 females) with IBD in the area of Oslo, Norway from October 2020 to December 2020. Participants were diagnosed with IBD for at least 6 months. The analysis of the interviews was guided by thematic analysis.

Results: In general, patients expressed a need for more dietary guidance. Participants met various health professionals during their follow-up, such as general practitioners, gastroenterologists and, sometimes, clinical dietitians. Some patients strived to receive follow-up by a clinical dietitian. They often experienced that health professionals had little knowledge and motivation to provide them with dietary guidance related to IBD. They often felt left alone and self-responsible to find dietary guidance in other informational sources or tried different diets on their own.

Conclusions: This study indicated that patients with IBD need more dietary guidance by health professionals. Based on the participants responses there is a need for more involvement and engagement of health professionals with specific competences in dietary guidance for patients with IBD.

Key words: Inflammatory bowel disease, dietary guidance, qualitative research.

1 **Background**

2

3 The prevalence of Inflammatory bowel disease (IBD) has increased rapidly worldwide (1).
4 IBD affects 3.2 million people in Europe (2). The number of cases of IBD is also increasing
5 in Norway. Approximately 0,80% of the population (43 000) in Norway have the disease and
6 approximately 250 people get diagnosed with CD and 600 with UC annually (3),(4). IBD is a
7 collective name for two conditions that cause chronic inflammation of the gastrointestinal
8 tract: Crohn's disease (CD) and ulcerative colitis (UC) (5). Common symptoms for IBD
9 include rectal bleeding, weight loss, diarrhoea, pain and fever (6). The severity and the
10 regularity of symptom flareups depends on which part of the gastrointestinal tract that is
11 affected (6).

12

13 Follow-up and treatment of IBD patients varies in different countries (7). In Norway, people
14 with IBD are followed-up and treated in outpatient clinics by a specialist or nurse (8, 9).

15 Patients also need to be followed-up by their general practitioner (10). Dietary guidance is an
16 important pillar in the treatment of IBD (11, 12). Dietary guidance is meant to help
17 individuals select health-promoting diets; as well as guiding and motoring individuals
18 through different diet therapies (13, 14). Diet therapy can be defined as the practical
19 application of nutrition either as preventative treatment or as a cure (13). The goal of dietary
20 guidance for IBD patients is to decrease gastrointestinal symptoms and improve quality of
21 life, prevent malnutrition, osteoporosis, and macronutrient deficiencies (12, 15).

22

23 General dietary recommendations for patients with IBD include focusing on nutrient-dense
24 foods and modifying their diet based on disease activity, complications, and anatomy (16).
25 Currently, there is not enough evidence to recommend one specific diet to IBD patients (17).
26 However, some diets seem to help patients with IBD (17): the low FODMAP (fermentable
27 oligosaccharides, disaccharides, monosaccharides, and polyols) diet and the Specific
28 carbohydrate diet (17). The low FODMAP can be beneficial for reducing gastrointestinal
29 symptoms in patients with quiescent IBD (18). The specific carbohydrate diet (avoiding
30 grains, potato, yam, corn, sugar, dairy and most legumes) has shown to be promising as a
31 nutritional treatment; it has proven to be effective by decreasing inflammation and inducing
32 remission in Crohn's disease patients (19, 20).

33

34 Before starting a new diet, patients should be guided and followed up by a healthcare
35 provider with expertise in nutrition; in order to ensure a nutritionally complete diet which

36 avoids unnecessary food restrictions (21). The patient should be followed up by a health
37 professional with specific knowledge about dietary guidance for patients with IBD and who`s
38 role would be to motivate and make sure that the patient has an adequate nutritional diet (8).
39 However, not all hospitals in Norway have clinical dietitians to provide dietary guidance for
40 patients with IBD (22).

41

42 Knowledge about patients' and health professionals' experiences with and needs for dietary
43 guidance are sparse. International studies among patients with IBD show that dietary
44 guidance is important for them and that they are greatly interested in modifying their diet as a
45 part of their treatment (11, 23, 24). An American review showed that very few healthcare
46 professionals provide dietary guidance for IBD patients (25). There are some studies that give
47 insights into this topic (26, 27). These studies showed that the least focus was on dietary
48 information even though most patients considered dietary information to be important. Most
49 patients never received any formal dietary guidance (26, 27).

50

51 This qualitative study can provide valuable insight about how patients with IBD experience
52 talking about nutrition with their healthcare provider. This information can contribute to
53 better knowledge about IBD patients' experiences with dietary guidance among healthcare
54 providers and hopefully improve their understanding of patients' needs and thereby improve
55 their healthcare practice.

56

57 **Method**

58 We performed qualitative, individual interviews with a descriptive approach to gather
59 insights into how patients with IBD experience dietary guidance.

60 *Participants and interviewing*

61 10 participants, one male and nine females, were interviewed by XX. Table 1 provides
62 background characteristics of the participants. They were recruited through an invitation
63 which was published on the Norwegian National Association Against Digestive Diseases
64 (LMF)s website. A set of requirements had to be met in order to be selected for participation.
65 These were being in 18-50 years old (later expanded to 60) and having had the diagnosis IBD
66 for 6 month or longer. Because there were a lack of participants and several people above the
67 age of 50 wanted to participate in the study the age criteria was later expanded to 60 years
68 old. Each participant chose the location for their interview. Five of the interviews were

69 conducted via phone (because of the Covid-19 pandemic). We used a semi-structured
70 interview guide that was created by the project group (consisting of XY, XZ and XQ). In the
71 interview guide there were 3 introductory questions and the following four overall themes: 1.
72 Experiences with receiving advice about nutrition from an interdisciplinary health
73 professional team, 2. Experiences with receiving advice about physical activity from an
74 interdisciplinary health professional team, 3. Experiences and attitudes towards integrative
75 healthcare, 4. Interdisciplinary collaboration between health personnel. The interviews were
76 recorded on the app “Nettskjema-dictaphone”. Each interview lasted between 15-50 min and
77 was transcribed verbatim by XX. After the first interview, the project group made some small
78 changes in the wording of some questions in the interview guide. The recordings were
79 listened to and transcribed consecutively. This study is in accordance with the consolidated
80 criteria for reporting qualitative research (COREQ).

81

82 **Table 1.** Characteristics of the participants

Participant	Gender	Age	Diagnosis	Time since diagnosis	Been in contact with a clinical dietitian	Place of meeting clinical dietitian	Got advice from other health professionals
1	Female	41 years old	UC	2005	Yes	Secondary health service(hospital)	No/not mentioned
2	Female	33 years old	UC	2002	Yes	Secondary health service(hospital)	Yes
3	Female	35 years old	UC	2015	Yes	Not mentioned	Yes
4	Female	40 years old	CD	2020	No	-	No
5	Female	31 years old	UC	2008	Yes	Not mentioned	Yes
6	Male	31 years old	CD	2018	Yes	Not mentioned	Yes
7	Female	26 years old	CD	2012	Yes	Secondary health service(hospital)	Yes

8	Female	41 years old	UC	2017	Yes	Secondary health service(hospital)	Yes
9	Female	57 years old	UC	1985	No	-	Yes
10	Female	56 years old	CD	2018	Yes	Not mentioned	Yes

83

84 *Ethical considerations*

85 The [blinded information] approved the study. The study was conducted in accordance with
86 the research guidelines by [blinded information]. Initial contact with the participants was
87 conducted by XY. Then, XX scheduled interviews with them over e-mail or over the phone.
88 The patients were assured of confidentiality and the voluntary nature of participation
89 throughout the process. Prior to the interviews, participants had to either sign a written
90 consent form or send an email (in the case of phone interviews) where they consented to
91 participation.

92

93 *Analysis*

94 The thematic analysis described by Braun & Clark (2006) was used for the analysis and was
95 performed by XX and XZ. The analysis consists of six steps: First, the interview transcripts
96 were carefully read through to get familiar with the data by XX. Second, initial codes were
97 inductively generated based on phrases that were of clear importance for the study (e.g.,
98 related to the experience of discussing diet with healthcare providers) by XX. Third, relevant
99 codes were grouped together by similarity and then subsequently combined into potential
100 themes. Codes that were not relevant for the objectives of the study were discarded (e.g.,
101 information about other diagnosis). Fourth, themes were reviewed. XX and XZ made sure the
102 themes were useful and represented the data accurately. Some themes were combined, some
103 discarded or new ones were created. Fifth, the themes were defined and named by XX and
104 XZ. Sixth, the results from the data were written down by XX. NVivo 12 facilitated the
105 organisation of the codes and sub-themes

106

107

108 **Results**

109 In general, most participants received the advice to reduce or totally avoid certain food
110 groups by their GP or gastroenterologist. Some patients revealed that the food they react to
111 and the amount of these foods has changed over the course of their disease. We identified 3
112 main themes surrounding the participants experiences with dietary guidance: 1) More need
113 for dietary guidance, 2) Experiences of dietary guidance perceived by clinical dietitians and
114 3) experiences with dietary guidance from other health professionals. Each of these themes
115 had subthemes as shown in table 2.

116

117 **Table 2.** Themes and subthemes

Theme	Subtheme
More need for dietary guidance	<ul style="list-style-type: none">● Were told to figure things out for themselves when it came to nutrition● Felt the need to take personal initiative to make changes to their diet as a part of their treatment● Wanted to change their diet in order to relieve symptoms● Used sources other than health professional for information about nutrition● experienced that the level of knowledge regarding nutrition is low among health professionals
Experiences of receiving dietary guidance from a clinical dietitian	<ul style="list-style-type: none">● The dietitian confirmed their personal experiences with certain foods● Appreciated getting dietary advice and being followed up by a dietitian● Felt that the clinical dietitian had little knowledge about diet in regard to IBD● Challenging to get in contact with a clinical dietitian

Experiences with dietary guidance from other health professionals

- Other health professionals have talked little about nutrition
- Received dietary advice regarding food and nutrition from their GP or gastroenterologist
- Other health professionals recommended the low FODMAP diet
- Experienced that health professionals have not been positive to the use of dieting as part of their treatment

118

119

120 *More need for dietary guidance*

121 Most patients expressed a need for more dietary guidance. A couple of patients wanted to
122 make dietary changes in hope that it would improve energy levels and symptoms. One female
123 patient who was diagnosed for 16 years found it disappointing that dietary guidance has been
124 so absent and wanted to talk to a dietitian or nutritionist, as illustrated by the following
125 statement:

126

127 “So, I’m disappointed. Very disappointed because I would’ve really liked to, eh, maybe, get
128 some advice” (No.1)

129

130 One patient wished that diet therapy, also was offered as treatment, and not only drug
131 therapy. Further, the patient wished that the health care system was more open to using diet
132 as a part of treatment.

133

134 Some patients were given small pieces of advice about nutrition but were barely provided any
135 meaningful dietary guidance. E.g., the doctor gave one patient a paper about low FODMAP
136 but did not mention anything about how the diet works or should be executed. Several
137 patients were told by their doctor to figure things out on their own. A female patient who was
138 diagnosed for 6 years described that their doctor only mentioned nutrition when she first got
139 the diagnosis:

140

141 “No, I think it was mentioned when I first got the diagnosis. The doctor told me “Yeah, some
142 people have experienced that certain foods can give similar symptoms, and, but it's very
143 individual, so you have to figure out this on your own” (No.3)

144

145 To some patients, the advice given to them by a dietitian was not very helpful. The patient
146 said the advice given did not provide any new information, and the patient felt like the advice
147 might have been useful 10 years ago:

148

149 “But...I felt like she did not provide any information I hadn't already found myself doing
150 research” (No.3)

151

152 Most patients felt like they had to take a lot of personal responsibility to get the information
153 about nutrition they wanted or needed. Patients reported using other sources for information
154 about nutrition than health professionals, and changes they made in their diet was because of
155 personal initiative.

156

157 For the majority of the patients the internet and personal experiences were the most important
158 sources of information about nutrition. Some patients reported reading low FODMAP blogs,
159 searching the internet and joining Facebook groups for people with IBD, friends, other people
160 with IBD, books and public talks.

161

162 “I google most things (...) that, and personal experiences, I quickly made myself some
163 experience with what worked and what did not” (No.5).

164

165 Several patients made changes to their diet without guidance from a healthcare provider.
166 They experienced improvements in their symptoms after making some adjustments to their
167 diet. One patient adapted his diet on personal initiative and felt like it works really well:

168

169 “I heard and experienced myself, that it works extremely well, with an adapted diet, but I
170 wasn't told “Yes, this is what you really should be doing” (No.6)

171

172 Some patients felt, or got the impression, that the level of knowledge about what patients
173 with IBD should be eating was very low among the health professionals involved in their
174 care. One patient felt like it was obvious that the doctor's level of competence regarding

175 nutrition was low and therefore should not give dietary advice. Another patient said it was
176 apparent that the doctor did not have knowledge nor was interested in getting knowledge
177 about nutrition:

178

179 “I don't think they have a lot of knowledge about what type of foods, well, the doctors
180 obviously did not have a lot of knowledge and were obviously not interested in gaining
181 knowledge either, about it, I think” (No.8)

182

183 *Experiences with receiving dietary guidance from a clinical dietitian*

184 Participants described their experience with a clinical dietitian as both valuable and
185 unhelpful. Having their experiences with various foods confirmed and perceiving individual
186 advice were qualities that made the encounter a positive experience. Negative experiences
187 were associated with the lack of IBD-specific dietary guidance, and problems getting a
188 referral to clinical dietitian. Some patients expressed that the clinical dietitian did not have
189 the expertise to give them IBD-specific dietary guidance.

190

191 To one patient their meeting with the clinical dietitian was described as providing the feeling
192 of relief. The patient was worried she was weird as she thought she was a picky eater, but the
193 clinical dietitian reassured her the picky eating was because of the disease:

194

195 “For the most part, I would say there was one thing, a pile of things I didn't handle so well,
196 and she would confirm, “yes, you're not picky, it's your body telling you it doesn't want this
197 food because it's actually making you ill. (no.7)”

198

199 Several patients felt that the dietitian had little knowledge about nutrition and IBD. Some
200 patients had experienced that the dietitian was unsure about giving specific advice and had
201 little knowledge about the effects of nutrition on IBD, as illustrated by the following
202 statement:

203

204 “ehm, the clinical dietitian, about the connection between IBD and nutrition (...) I don't think
205 she was very (...), I don't think there was, not a lot of knowledge there” (No.8).

206

207 Problems getting a referral to a clinical dietitian involved not being offered contact with a
208 clinical dietitian by their GP and having to convince their gastroenterologist to give them a

209 referral to a clinical dietitian. One patient wanted contact with a dietitian early on in their
210 treatment but had to make a case for themselves to get a referral from their gastroenterologist.
211 The experience of having to fight for a referral was described as disappointing and gave the
212 feeling of not being heard:

213

214 “Yes, in a way I had to, not fight for it, but I almost had to talk them into it” (No.6)

215

216 *Experiences with dietary guidance from other health professions*

217 Some patients said that they had not received any dietary guidance by their GP,
218 gastroenterologist or nurse. Patients reported that their diet was often just briefly discussed
219 and for some patients some of the advice given was unhelpful as they were not tailored to
220 them. Just one patient said the advice received helped with symptoms.

221

222 If a patient received dietary guidance by a gastroenterologist or GP, they were usually
223 advised to avoid certain foods. The advice perceived varied from patient to patient, and some
224 were told to avoid milk, gluten, sugar, vinegar, white flour, mushrooms, yeast, steak and
225 whole wheat and seeds products in bad periods.

226

227 One patient was advised by their gastrosurgeon to eat more fibre despite explaining to the
228 gastrosurgeon that fibre would make them even more constipated. The patient felt frustrated
229 and said it was stupid of the gastrosurgeon to even suggest it:

230

231 “Jesus Christ, I have been sitting here, telling you, the more fibre I eat the more constipated I
232 become!” (No.7)

233

234 One patient was told not to get food poisoning when asking for dietary guidance:

235

236 “I said to one gastroenterologist, “what should I eat, what shouldn't I eat and what should I
237 do? And he just said, “Just try to avoid getting food poisoning” (No.8).

238

239 One patient had experienced that some of the advice given was helpful in reducing
240 symptoms. The patient was recommended, by a doctor at a private clinic, to take cod liver oil,
241 with other pills, to help with tiredness.

242

243 A few patients were advised to try the low FODMAP diet. For several patients the diet was
244 not suggested or recommended in the initial stages of treatment or follow-up. None of the
245 patients, except for one, stated how this diet impacted their disease activity. As illustrated by
246 the following statement:

247

248 “(...) low FODMAP, but it didn't work for me at all, I didn't feel like it (...) I didn't get any
249 better, it didn't do anything, no changes in my stomach” (No.10)

250

251 Some patients reported meeting a gastroenterologist who meant that following specific diets
252 was useless in treating their symptoms or that dieting in relation to IBD was just nonsense.
253 The gastroenterologist to one patient insisted on a treatment only consisting of drug therapy.
254 One patient experienced that the gastroenterologist was not interested in how they eat or how
255 the patient managed to reduce symptoms through dietary modifications:

256

257 “The doctors I have encountered, they aren't interested in... the nutritional part at all” (No.3)

258

259 **Discussion**

260 This study aimed to explore how patients with IBD experienced receiving dietary guidance
261 by different health professionals. The findings of this study indicated that there was a
262 discrepancy between IBD patients' needs for dietary guidance and the dietary guidance they
263 received. Patients often felt that they themselves were responsible for finding out which foods
264 helped reduce their symptoms. Many patients were told by their GP or gastroenterologist to
265 figure things out by themselves when it came to nutrition. Patients who received dietary
266 guidance from gastroenterologists or GPs felt that the level of knowledge about nutrition for
267 IBD patients was low. They also experienced that these health professionals had a negative
268 attitude towards using dietary guidance as part of their follow-up. Patients often wanted to
269 meet a clinical dietitian. However, patients who had received dietary guidance from a clinical
270 dietitian could also experience little knowledge about IBD.

271

272 *Need for more dietary guidance*

273 Our findings are in accordance with previous studies show that IBD patients ask for more
274 dietary guidance (23, 27, 28). For example, (26) developed a questionnaire assessing
275 demographics, dietary perceptions and behaviours among 400 IBD patients attending an IBD
276 clinic in Manchester, UK. Similar to the findings in our study, this study showed that nearly

277 half of the patients had never received dietary guidance. The results of (26) also showed that
278 the majority (67%) wanted further dietary guidance. This is also reflected in our study where
279 several patients reported not getting enough dietary guidance. Furthermore, several patients in
280 our study were told by their gastroenterologist or GP to figure out things regarding nutrition
281 for themselves. A Canadian cohort study investigated informational needs and preferences
282 among 271 patients with longstanding IBD (27). In this study dietary guidance was regarded
283 as important by the majority. Only 8-16% of the patients in the study of (27) perceived to
284 receive adequate dietary guidance. Results from Wong et al. also showed that the majority of
285 patients (60 to 68%) believed that more dietary guidance would be beneficial.

286

287 An Australian cross-sectional study looked into the attitudes towards diet of 928 IBD patients
288 and 136 clinicians (23). The majority of patients in this study assumed that their diet affected
289 their IBD. Similarly, several patients in our study believed diet could relieve symptoms or
290 experienced that an adapted diet reduced the need for medication. However, since we did not
291 do a study on the effects of an adapted diet on the use of medication, we cannot discuss if
292 certain dietary changes can affect medication usage in IBD patients. (23) also found that only
293 26% of patients reported receiving dietary guidance and most patients (61%) felt that their
294 healthcare provider did not emphasise the role of diet. Interestingly, (23) found that almost all
295 of the healthcare providers reported giving dietary guidance. There were similar results in
296 both our study and that of (23) study; patients in our study also felt that their
297 gastroenterologist did not care about the role of diet as part of their treatment.

298

299 This was not the case for patients in a Dutch study (28). The study was a self-administered
300 online questionnaire aimed at investigating the perspectives of 294 adult Dutch patients with
301 IBD in regard to dietary guidance (28). In contrast to our study, as well as others (23, 26, 27)
302 the findings in this study showed that the majority had received dietary guidance (mostly
303 from dietician and medical specialist). In addition, most patients (70%) who had received
304 dietary guidance were satisfied with it (28). (28) found that 59% valued nutrition more than
305 or equally as important as medications, while 62% believed diet was more important in
306 managing their disease. These findings correlate with previous studies (23, 26, 27) and our
307 own study where results show that patients consider diet to be important. In keeping with the
308 findings of (26),(27) and (23) our participants felt that dietary guidance was not adequately
309 addressed. In addition, participants were of the opinion that dietary guidance is an important
310 part of their disease management. Taken together, dietary guidance seems to be very

311 important to the IBD patients, but the majority of patients are not provided dietary guidance,
312 or the dietary guidance provided is inadequate.

313

314 *Perceived knowledge among health professionals*

315 Some participants in our study felt that their healthcare providers had little knowledge
316 relating to nutrition; An American review summarizing the latest evidence around frequently
317 used diets among IBD patients, highlights the diets with known efficacy and provide
318 guidance to practitioners (25). According to the review, the absence of dietary guidance is
319 partly caused by the lack of knowledge about nutrition among the healthcare providers and
320 limited available dietary guidelines based on prospective data (25). In contrast, (24) found
321 that 170 out of 202 healthcare providers in the US (registered dietitians, gastroenterologist,
322 nurses) ranked their knowledge on IBD nutrition as “Very good” (81/202) or “good”
323 (89/202). The study also found that 64% reported discussing nutrition with their patients
324 routinely, 32% occasionally (if they suspected an issue) and 3.5% did only if the patient
325 brought it up (24).

326

327 In our study, several had met with a dietitian. Some patients indicated that they did not think
328 that the clinical dietitian had any knowledge about IBD-nutrition and one patient also
329 described the advice they received as outdated. Similarly, patients of (24) had expressed
330 concerns regarding the level of knowledge among the dietitians. Patients reported being
331 concerned about the dietitian not always having enough knowledge about some of the unique
332 nutrition-related aspects of IBD. Interestingly, 86.7% of the dietitians reported having “very
333 good” knowledge about IBD-nutrition. (24) also gives the unique view of the dietitians
334 regarding dietary guidance. (23) provides the view of some dietitians, but the study focuses
335 on their attitude towards diet rather than their experiences with providing dietary guidance;
336 this is not explored in ours or the other studies (26-28). The dietitians described being
337 unprepared to handle specific IBD-related nutritional care as information about this is not
338 provided for them in their formal training (24).

339

340 Some patients in our study felt that their healthcare provider had a negative attitude towards
341 diet therapy as part of their treatment; They believed that their gastroenterologist was not
342 interested in nutrition or did not think it was important in the management of symptoms. This
343 is reported in the study of (24), where less than half (49%) of gastroenterologists thought
344 nutrition was “very important” in IBD management. However, providers reported not

345 receiving adequate education about IBD-nutrition in their training and therefore only being
346 comfortable giving basic recommendations (24). Less than half felt they had adequate
347 nutritional care resources to initiate and provide dietary guidance. Additionally, time scarcity
348 was reported as being a major barrier in providing dietary guidance.

349

350 The findings indicate that lack of dietary guidance is caused by IBD-nutrition not being a part
351 of healthcare providers education. However, since our study only investigated the
352 experiences of the patients, we should perform a knowledge study among healthcare
353 providers to better assess their IBD-nutrition knowledge.

354

355 *Important sources for dietary information about IBD*

356 In our study, as a result from not receiving adequate dietary guidance from their healthcare
357 provider, many sought dietary guidance elsewhere, such as the internet. Many patients were
358 told to figure out things on their own and some patients also said that they wished they
359 received more support/dietary guidance, especially when they were initially diagnosed. The
360 majority of patients in our study reported their personal experiences with food and/or the
361 internet as the most important source for nutritional information. Similar to our study, (28)
362 found that for the majority (81%) personal experience was their main sources of nutritional
363 information. More than half sought out information online according to (24). Contrasting,
364 findings from (26) showed that only 8% reported using the internet, but interestingly, only a
365 few patients receive nutritional information from dietitians or gastroenterologists (31% and
366 17% respectively). In contrast with (24, 26, 28) and our own study, almost all of the patients
367 (91%) had been referred to dietitian according to (23).

368

369 Based on these findings there seems to be a link between not receiving dietary guidance and
370 seeking out dietary guidance online. There is no one specific “IBD-diet” that works for every
371 IBD-patient (17), but there is plenty of information about how to treat IBD through dietary
372 guidance online. A patient without guidance might followed unverified advice leading to
373 them executing certain diets wrong or avoid one or more food groups. Therefore, there is a
374 risk that patients who do not receive dietary guidance and thus, seek information online,
375 might be practicing unnecessarily restrictive eating (29). Dietary guidance should therefore
376 be provided in person by qualified health professionals, not only to inform the patients on
377 what they can eat, but also to guide them and prevent them from seeking unprofessional
378 advice online (8, 21).

379

380 In our study, patients did not directly disclose the preferred source for dietary guidance, but
381 very few of the patients described using health professionals as a source. However, the
382 majority of the patients wanted dietary guidance and wished their GP or gastroenterologist to
383 give dietary guidance higher priority. These findings could indicate that the patients in our
384 study would prefer dietary guidance from their GP and/or gastroenterologist. Similarly, most
385 patients in (26) study preferred dietitian (45%), IBD nurse specialist (36%),
386 gastroenterologist (29%) and primary care physicians (15%) as sources for nutritional
387 information (26). The preferences of patients in (27) study was similar to that of the patients
388 in (26) and our own study; namely medical specialists (81%) and family doctors (64%) were
389 regarded as some of the most acceptable informational sources (27).

390

391 The findings show that patients want guidance from a healthcare provider. Further, many
392 patients trust their healthcare provider to give them the correct information and the
393 information they want.

394

395 *Strengths and limitations*

396 One strength of this study is the qualitative approach. Qualitative approaches fit well when
397 we want to study topics that have not been well studied before (30). Further, qualitative
398 interviews are fitting when you want insight into how people experience and view on their
399 situation (30). In this study we were able to obtain detailed descriptions of the participants'
400 experiences, which provided rich details that are not possible using quantitative instruments
401 and methods. Another strength is that throughout the study, the findings were assessed by
402 more than one researcher. During the analysis, the themes derived from data and our
403 understanding of the data was regularly presented and discussed with experienced
404 researchers. The age range of the participants is also a strength. The inclusion of both
405 younger and older participants we got insight in how dietary guidance is incorporated in
406 treatment today, as well as 10-20 years ago.

407

408 One limitation with our study is that half of the interviews were conducted over the phone.
409 These interviews might not have been as informative compared to the face-to-face interviews
410 because of missing out on nonverbal communication. Cell reception also affected the
411 interviews. The cell reception in two of these interviews were bad which affected the clarity

412 of the voice and subsequently the quality of the interviews. In addition, the study was limited
413 to a Norwegian context, which may affect the transferability of the results. However, several
414 former studies (23, 26, 27) show that IBD patients generally do not receive sufficient dietary
415 guidance from health personnel. Therefore, the findings in this study can probably be
416 representative to other patients with IBD in similar situations.

417

418 **Conclusions**

419 In conclusion, this study indicated that dietary guidance is a major need for patients with
420 IBD. Many patients felt they were left to themselves and were not supported when it comes
421 do dietary changes. The patients encounter several healthcare professionals during follow-up,
422 but the majority do not receive sufficient dietary guidance. Healthcare providers should listen
423 and pay attention to the patient's treatment preferences and actively encourage conversations
424 about nutrition with willing patients. Clinical dietitians and other health personnel with
425 expertise in nutrition should provide patients with IBD with more dietary guidance. Together
426 with more focus on IBD in their education and the right specialized training, they can provide
427 higher quality dietary guidance for IBD patients.

428

429

430 **Abbreviations**

431 **IBD:** Inflammatory Bowel Disease

432 **CD:** Crohn's disease

433 **UC:** Ulcerative colitis

434 **LMF:** Norwegian national association against digestive diseases

435 **NSD:** Norwegian centre for research data

436

437

438 **Declarations**

439

440 **Ethic approval and consent to participate**

441 Ethical approval was obtained by the Norwegian Center for Data Security (Nr 505238).

442 Participants gave their written informed consent to participate.

443

444 **Consent to publication**

445 Not applicable

446

447 **Availability of data and materials**

448

449 The datasets used and analysed during the current study are available from the corresponding
450 author on reasonable request.

451

452 **Competing interests**

453

454 None declared.

455

456 **Funding**

457

458 Not applicable.

459

460 **Authors' contributions**

461 AS, LGH, KS, HE participated in the planning of the study; AS, LGH conducted the analysis;
462 AS, LGH, KS, HE interpreted the findings of the study; AS has written the manuscript.

463

464

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Table 1: Example of how codes are put into sub-themes and main themes

Text in the transcript	Codes	Sub-themes	Main themes
<p>“I don't believe they had a lot of knowledge about what food, well, the doctors obviously did not have knowledge and they obviously didn't want to gain knowledge, about it(nutrition), I think”</p> <p>“In the beginning, I was told “No, it varies what people can eat and can't eat. So, you just have to figure it out by yourself””</p>	<p>Do not believe the doctors she has encountered in her follow-up have a lot of knowledge about food and nutrition</p>	<p>Have experienced that the level of knowledge among healthcare providers in regard to nutrition is low</p>	<p>Have not received sufficient dietary guidance</p>

Part 2 (article):

Table 1: Background data of the participants

Participant	Gender	Age	Diagnosis	Time since diagnosis	Been in contact with a clinical dietitian	Place of meeting clinical dietitian	Got advice from other health professionals
1	Female	41 years old	UC	2005	Yes	Secondary health service(hospital)	No/not mentioned
2	Female	33 years old	UC	2002	Yes	Secondary health service(hospital)	Yes
3	Female	35 years old	UC	2015	Yes	Not mentioned	Yes
4	Female	40 years old	CD	2020	No	-	No
5	Female	31 years old	UC	2008	Yes	Not mentioned	Yes
6	Male	31 years old	CD	2018	Yes	Not mentioned	Yes
7	Female	26 years old	CD	2012	Yes	Secondary health service(hospital)	Yes
8	Female	41 years old	UC	2017	Yes	Secondary health	Yes

						service(hospital)	
9	Female	57 years old	UC	1985	No	-	Yes
10	Female	56 years old	CD	2018	Yes	Not mentioned	Yes

Table 2: Themes and subthemes

Theme	Subtheme
More need for dietary guidance	<ul style="list-style-type: none">● Were told to figure things out for themselves when it came to nutrition● Felt the need to take personal initiative to make changes to their diet as a part of their treatment● Wanted to change their diet in order to relieve symptoms● Used sources other than health professional for information about nutrition● experienced that the level of knowledge regarding nutrition is low among health professionals
Experiences of receiving dietary guidance from a clinical dietitian	<ul style="list-style-type: none">● The dietitian validated their personal experiences with certain foods● Appreciated getting dietary advice and being followed up by a dietitian● Felt that the clinical dietitian had little knowledge about diet in regard to IBD● Challenging to get in contact with a clinical dietitian
Experiences with dietary guidance from other health professionals	<ul style="list-style-type: none">● Other health professionals have talked little about nutrition● Received dietary advice regarding food and nutrition from their GP or gastrologist● Other health professionals recommended the low FODMAP diet

- | | |
|--|---|
| | <ul style="list-style-type: none">● Experienced that health professionals have not been positive to the use of dieting as part of their treatment |
|--|---|

Appendix 1: E-mail sent to the Norwegian centre of research data (NSD)

Godkjenning i NSD er fra 31.01.2020 med referansenummer 697660. Så ved utvidelse fra 50 til 60 år, står det følgende på siden:

- **Melding fra Lise Aasen Haveraaen** 19.11.2020 11:48

Hei, Viser til telefonsamtale i dag angående endringene beskrevet i melding 18.11.2020. Forstår at dere vil rekruttere personer i aldersgruppen 18-60 år (tidligere 18-50 år), og at intervjuene vil gjennomføres over telefon. Vi tar endringene til orientering. Endringene medfører ikke en endring i vår vurdering, og dere trenger ikke å sende inn endringsmelding på dette. Lykke til videre med prosjektet! Vennlig hilsen, Lise, NSD

- **Melding fra Kari Skrautvol** 18.11.2020 15:19

Vi er i gang med intervju av informanter nå og grunnet Covid-19 foretas intervjuer både fysisk og med telefon. Det er behov for å øke antall intervjuer fra 15 til 20 informanter som rekrutteres gjennom Landsforeningen for fordøyelsessykdommer. Det har meldt seg flere informanter i aldersgruppen 50 til 60 år. Forskergruppen har diskutert dette og vi ønsker å utvide aldersspennet fra 18 til 60 år. Det er i dag rettet opp i prosjektplan og i samtykkeskjemaet som informanten underskriver fysisk. Som prosjektleder ønsker jeg da bekreftelse fra dere at dette er i orden. 18.11.20 Kari Skrautvol

Appendix 2: Interview guide before revision

Innledende spørsmål

Hvor lenge har du hatt IBD?

Kan du fortelle meg om hvor du har fått oppfølgingen av IBD, og om dine generelle erfaringer med din oppfølging?

Kan du fortelle litt om deg selv?

Tema 1) Erfaringer med å få råd om kosthold fra et tverrfaglig helseprofesjonsteam

Er du opptatt av å spise sunt?

Hva er dine viktigste informasjonskilder for hva du skal spise?

Kan du fortelle meg om dine erfaringer med å få råd om kosthold i det offentlige helsevesenet?

Hvordan føler du at de rådene du har fått tar hensyn til din situasjon eller hverdag?

Tema 2) Erfaringer med å få råd om fysisk aktivitet fra et tverrfaglig helseprofesjonsteam

Er du glad i å være aktiv?

Hva er dine viktigste informasjonskilder for fysisk aktivitet?

Kan du fortelle meg om dine erfaringer med å få råd om fysisk aktivitet i det offentlige helsevesenet?

Hvordan føler du at de rådene du har fått tar hensyn til din situasjon eller hverdag?

Tema 3) Erfaringer med og holdninger til integrerende helseomsorg

Har du erfaringer med komplementær behandling som akupunktur, homeopati eller lignende energibehandling i forhold til IBD?

Hvis ja, kan du fortelle meg om dine erfaringer med dette? Har du fått råd om kosthold og/eller fysisk aktivitet der?

Hvis nei, kan du fortelle meg hvorfor du ikke har oppsøkt det?

Hva tenker du om komplementær behandling som supplement til den omsorgen du får fra det offentlige helsevesenet og hvorfor bør helsepersonell lytte til dine erfaringer?

Tema 4) Samarbeid med annen helsepersonell

Hvordan opplever du samarbeid med andre helseprofesjoner?

Appendix 3: Interview guide after revision

Intervjuguide personer med IBD

Revisjon av spørsmålene etter første intervju, 9.10.20 Kari Skrautvol

Innledende informasjon om prosjektet, personvern og signering av samtykkeskjema

Innledende spørsmål:

Hvor lenge har du hatt IBD?

Kan du fortelle meg hvor du har fått oppfølging for IBD og om dine generelle erfaringer med din oppfølging?

Hvordan opplever du samarbeid med andre helseprofesjoner?

Tema 1) Erfaringer med å få råd om kosthold fra et tverrfaglig helseprofesjonsteam

Hvilke erfaringer har du i forhold til kosthold?

Hvilke erfaringer har du i forhold til råd om kosthold?

Hva er dine viktigste informasjonskilder for hva du skal spise?

Du har allerede fortalt om din oppfølging av IBD. Kan du fortelle meg om dine erfaringer med å få råd om kosthold fra helsepersonell som du har møtt i løpet av din oppfølging?

Hvordan føler du at de rådene du har fått tar hensyn til din situasjon eller hverdag?

Tema 2) Erfaringer med å få råd om fysisk aktivitet fra et tverrfaglig helseprofesjonsteam

Hvordan opplever du å være aktiv i hverdagen?

Hva er dine viktigste informasjonskilder for fysisk aktivitet?

Har du snakket om fysisk aktivitet med helsepersonell som du har møtt i løpet av din oppfølging av IBD?

Hvordan føler du at de rådene du har fått tar hensyn til din situasjon/hverdag?

Tema 3) Erfaringer med og holdninger til integrerende helseomsorg

Har du erfaring med andre behandlingsformer (som for eksempel naturmedisin, akupunktur og homeopati) utenfor helsevesenet?

Hvis ja, kan du fortelle oss om dine erfaringer med det? Har du fått råd om kosthold og/eller fysisk aktivitet der?

Hvis nei, kan du fortelle oss hvorfor du ikke har oppsøkt det?

Hva tenker du om andre behandlingsformer som supplement til den helsehjelpen du får fra det offentlige helsevesenet og hvorfor bør helsepersonell lytte til dine erfaringer?

Tema 4) Tverrfaglig samarbeid mellom helsepersonell og samhandling

Har du tanker om på hvilken måte de offentlige helsetjenester kan bli bedre?

Er det noe du vil si oss som du har tenkt på før møtet i dag eller under intervjuet?

Appendix 4: Original application application to NSD



Meldeskjema 697660
Sist oppdatert

31.01.2020

Hvilke personopplysninger skal du behandle?

- Navn (også ved signatur/samtykke)
- Fødselsdato
- Adresse eller telefonnummer
- E-postadresse, IP-adresse eller annen nettidentifikator
- Lydopptak av personer
- Andre opplysninger som vil kunne identifisere en fysisk person

Type opplysninger

Du har svart ja til at du behandler andre opplysninger som vil kunne identifisere en person, beskriv hvilke

I et innledende spørsmål på intervjuguiden med pasienter legger vi til et spørsmål om hvor de forteller om seg selv. Svaret inngår da i dette intervjuet. Dette handler om generell informasjon om hvem pasienten er. Det vil ikke bli spurt om slektninger har IBD.

Skal du behandle særlige kategorier personopplysninger eller personopplysninger om straffedommer eller lovovertrедelser?

- Helseopplysninger

Prosjektinformasjon

Prosjektittittel

Pasienters og helsepersonells erfaringer med råd om kosthold, fysisk aktivitet og integrerende helseomsorg ved IBD i tverrfaglig rehabilitering

Dersom opplysningene skal behandles til andre formål enn behandlingen for dette prosjektet, beskriv hvilke

Opplysningene skal kun brukes inn i dette forskningsprosjektet.

Begrunn behovet for å behandle personopplysningene

Det er ikke behov for mer personopplysninger enn å kunne identifisere personen til intervjuet og at det fyller de kriteriet til alder. Videre at det er behov for å balansere mellom kjønn på intervju av pasienter. Det er ikke behov for helseopplysninger fra andre enn pasienten selv.

Ekstern finansiering

Type prosjekt

Forskerprosjekt

Behandlingsansvar

Behandlingsansvarlig institusjon

OsloMet - storbyuniversitetet / Fakultet for helsevitenskap / Institutt for sykepleie og helsefremmende arbeid

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Kari Skrautvol, kari.skrautvol@oslomet.no, tlf: 67236185

Skal behandlingsansvaret deles med andre institusjoner (felles behandlingsansvarlige)?

Nei

Utvalg 1

Beskriv utvalget

15 pasienter med IBD i aldersgruppen 18 til 50 år. De har hatt diagnosen IBD i seks måneder og over.

Rekruttering eller trekking av utvalget

Pasienter av begge kjønn rekrutteres gjennom Landsforeningen for fordøyelsessykdommer. Invitasjon legges ut på deres medlemside og det er fortløpende rekruttering. Det tilstrebes variasjon i alderssammensetning og balanse mellom begge kjønn.

Alder

18 - 50

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Nei

Personopplysninger for utvalg 1

- Navn (også ved signatur/samtykke)
- Fødselsdato
- Adresse eller telefonnummer
- E-postadresse, IP-adresse eller annen nettidifikator
- Lydopptak av personer
- Helseopplysninger

Hvordan samler du inn data fra utvalg 1?

Personlig intervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Grunnlag for å behandle særlige kategorier av personopplysninger

Uttrykkelig samtykke (art. 9 nr. 2 bokstav a)

Redegjør for valget av behandlingsgrunnlag

Informasjon for utvalg 1

Informerer du utvalget om behandlingen av opplysningene?

Ja

Hvordan?

Skriflig informasjon (papir eller elektronisk)

Utvalg 2

Beskriv utvalget

Helsepersonell med 5 års klinisk erfaring med pasientgruppen. Det er 15 helsepersonell som er leger, sykepleiere, ernæringsfysiologer og fysioterapeuter. De er ansatt ved en seksjon for pasienter som blir behandlet for IBD poliklinisk.

Rekruttering eller trekking av utvalget

Muntlig og skriftelig henvendelse til gastroterologisk seksjon ved tre sykehus i Helse SørØst og Vestre Viken. Personer til intervju blir rekruttert med fem

helsepersonell fra hvert sted, bestående av lege, sykepleier, emeringsfysiolog, fysioterapeut og en lege eller sykepleier i tillegg, samlet 5 personer

Alder

27 - 70

Inngår det voksne (18 år +) i utvalget som ikke kan samtykke selv?

Nei

Personopplysninger for utvalg 2

- Navn (også ved signatur/samtykke)
- Fødselsdato
- Adresse eller telefonnummer
- E-postadresse, IP-adresse eller annen nettidifikator
- Lydoptak av personer

Hvordan samler du inn data fra utvalg 2?

Personlig intervju

Grunnlag for å behandle alminnelige kategorier av personopplysninger

Samtykke (art. 6 nr. 1 bokstav a)

Informasjon for utvalg 2

Informerer du utvalget om behandlingen av opplysningene?

Ja

Hvordan?

Skriftlig informasjon (papir eller elektronisk)

Tredjepersoner

Skal du behandle personopplysninger om tredjepersoner?

Nei

Dokumentasjon

Hvordan dokumenteres samtykkene?

- Manuelt (papir)

Hvordan kan samtykket trekkes tilbake?

Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Hvordan kan de registrerte få innsyn, rettet eller slettet opplysninger om seg selv?

Så lenge du kan identifiseres i datamaterialet, har du rett til: - innsyn i hvilke personopplysninger som er registrert om deg, - å få rettet personopplysninger om deg, - få slettet personopplysninger om deg, - få utlevert en kopi av dine personopplysninger, - og å sende klage til personvernombudet eller Datatilsynet om bhenadlingen av dine personopplysninger.

Totalt antall registrerte i prosjektet

1-99

Tillatelser

Skal du innhente følgende godkjenninger eller tillatelser for prosjektet?

Behandling

Hvor behandles opplysningene?

- Fysisk isolert maskinvare tilhørende behandlingsansvarlig institusjon

Hvem behandler/har tilgang til opplysningene?

- Prosjektansvarlig
- Student (studentprosjekt)
- Interne medarbeidere

Tilgjengeliggjøres opplysningene utenfor EU/EØS til en tredjestat eller internasjonal organisasjon?

Nei

Sikkerhet

Oppbevares personopplysningene atskilt fra øvrige data (kodenøkkel)?

Ja

Hvilke tekniske og fysiske tiltak sikrer personopplysningene?

- Opplysningene anonymiseres
- Opplysningene krypteres under forsendelse

Varighet

Prosjektperiode

24.02.2020 - 31.12.2024

Skal data med personopplysninger oppbevares utover prosjektperioden?

Nei, data vil bli oppbevart uten personopplysninger (anonymisering)

Hvilke anonymiseringstiltak vil bli foretatt?

- Koblingsnøkkelen slettes
- Personidentifiserbare opplysninger fjernes, omskrives eller grovkategoriseres
- Lyd- eller bildeopptak slettes

Vil de registrerte kunne identifiseres (direkte eller indirekte) i oppgave/avhandling/øvrige publikasjoner fra prosjektet?

Nei

Tilleggsopplysninger

Etter tilbakemelding fra dere den 23.01 er informasjonsskrivene til begge utvalg rettet opp med prosjektslutt i 2024. Vi forholder oss aktivt til som forskere hvor helsepersonell har taushetsplikt. Det noteres spesielt i både databehandlingen og i skriving av masteroppgaver og i vitenskapelige artikler fra dette prosjektet. Etter tilbakemelding 29.01.2020 er intervjuguide til utvalg 1 lagt til et innledende spørsmål. I samtykkeerklæringen er det rettet opp med at datamaterialet anonymiseres ved prosjektslutt, som etter planen er innen utgangen av 2024

Appendix 5: Consent form

Vil du delta i forskningsprosjektet

'Pasienters og helsepersonells erfaringer med råd om kosthold, fysisk aktivitet og integrerende helseomsorg ved IBD i tverrfaglig rehabilitering'

Dette er et spørsmål til deg om å delta i et forskningsprosjekt om pasienters erfaringer med å få råd om kosthold, fysisk aktivitet og integrerende helsehjelp til pasienter med IBD. I dette skrevet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Hensikten med prosjektet er å få økt kunnskap om hvordan pasienter erfarer å få råd om kosthold, fysisk aktivitet og samtale om dine erfaringer om du har fått hjelp av integrerende helsehjelp som akupunktur, naturmedisin inkludert homeopati eller psykosomatiske metoder. Gjennom at pasienter med IBD deler slike erfaringer ønsker vi å få en bedre innsikt i hvilke helseråd som gis, hvor helseinformasjonen hentes fra og hvordan denne informasjonen blir gitt og hvordan den oppleves å bli mottatt. I denne studien er målet er å få økt kunnskap om hvordan pasienter og helsepersonell erfarer og forholder seg til dagens helseråd og til nyere kunnskap innen integrerende rehabilitering som innebærer å gi råd og å få råd i en kontekst som IBD skolen er.

Studien er en del av et større forskningsprosjekt som inkluderer både pasienter og helsepersonell ønsker i forhold til råd om kosthold, fysisk aktivitet og integrerende helsehjelp.

Omsorg, pleie og behandling av akutt og kronisk inflammatorisk tarmsykdom forandrer seg nå til å følge mer utviklingen av lidelsen med nyere medisinske behandlingsmetoder og med større oppmerksomhet mot ernæring, fysisk aktivitet og egenomsorg gjennom utdanning og helseveiledning. I integrerende helsehjelp ligger komplementære metoder som kan bli brukt som supplement til tradisjonell behandling og kan hjelpe å lette pasientsymptomer. Det er behov for forskning på erfaringer fra pasienter og helsepersonell for å validere disse tilnærmingene.

I prosjektet vil man inkludere masterstudenter i sykepleie, fysioterapi og samfunnsnærings som vil gjennomføre intervjuene. Intervjudataene vil inngå i og være utgangspunktet for deres masteroppgaver. Intervjuene vil foregå som en samtale mellom deg og intervjuer hvor vi er opptatt av du fritt skal få dele dine erfaringer.

Dette er et forskningsprosjekt som har en tverrfaglig forskergruppe av helsepersonell og vil sammen med masterstudenter innen tre helseprofesjoner skrive masteroppgaver under veiledning av forskerne. Deretter vil det bli skrevet tre vitenskapelige artikler i internasjonale vitenskapelige tidsskrifter og på grunnlag av dette bidra inn i det videre arbeidet for å utvikle konseptet rundt IBD skolen som et helsetjenestetilbud.

Hvem er ansvarlig for forskningsprosjektet?

Ansvarlig for prosjektet er Kari Skrautvol, førstelektor ved Institutt for sykepleie og helsefremmende arbeid ved OsloMet. Hun har lang erfaring med pasientgruppen og med studentinvolvering.

Prosjektet er knyttet til en tverrfaglig gruppe ved Fakultet fra helsefag på OsloMet. Kari Skrautvol (sykepleier og 1.lektor), Lisa Garnweidner-Holme (ernæringsfysiolog og 1.amanuensis) og Hedda Eik (fysioterapeut og 1.amanuensis) har alle erfaring med klinisk arbeid samt forskning og undervisning.

Intervjuene av pasienter vil bli foretatt ved OsloMet Storbyuniversitetet ved Fakultet for helsevitenskap. Pasienter er rekruttert gjennom Landsforeningen for fordøyelsessykdommer. Prosjektet vil intervju helsepersonell ved tre sykehus i Helse SørØst og Vestre Viken.

Hvorfor får du spørsmål om å delta?

Vi henvender oss til deg fordi du har erfaring med å leve med IBD. Vi ønsker at du har minimum 6 måneders erfaring etter klinisk diagnose med inflammatorisk tarmsykdom og er i alder mellom 18 og 50 år. Det er ønskelig at du har erfaringskunnskap med maten du spiser, fysisk aktivitet og eventuelt supplerende metoder i tillegg til den medisinske behandlingen du får.

Dere som er invitert til å delta er rekruttert etter skriftlig henvendelse til Landsforeningen for fordøyelsessykdommer og med invitasjon til deltakelse på deres hjemmesider. Vi har tatt kontakt med seksjoner ved OUS, Ahus og Vestre Viken som følger opp deres pasientgruppe og vil intervju helsepersonell ved tre sykehus. Det er ønskelig med en balansert fordeling mellom kjønn og alder i forhold til dere som blir rekruttert for intervju.

Hva innebærer det for deg å delta?

Metoden er en intervjustudie. Det vil si at samtalen mellom deg og masterstudent vil bli tatt opp på lydopptak. Det er kun masterstudenten som gjør intervjuet og veiledere som har tilgang på intervjuet.

Intervjuet innebærer at du må sette av ca. 1,5 time på et avtalt sted med studenten.

Intervjuet blir etterpå profesjonelt transkribert og person, navn og sted for intervju er anonymisert. Det er kun en kode med kjønn, alder og IBD diagnose som blir beholdt på det transkriberte intervjuet.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrevet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

Det er kun forskergruppen og masterstudentene som intervjuer som har tilgang til persondata og intervjuene. Persondata blir holdt adskilt fra de transkriberte intervjuer. Persondata og lydfiler blir låst inn i sikret safe ved OsloMet under prosjekt perioden. Intervjuene blir lagret transkribert, anonymisert og sikret på egne bærbare PC maskiner som tilhører OsloMet og er klargjort for formålet de skal brukes til ved videre behandling og analyse av forskningsdata. Deltakerne vil ikke kunne gjenkjennes i publiserte artikler og utsagn som eventuelt blir benyttet i resultatpresentasjon er anonymisert.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Prosjektet skal etter planen avsluttes 31.12.2022. Datamaterialet er anonymisert med kode både på navn og bosted blir slettet etter to år etter avslutning, innen 31.12.2024. Det samme gjelder personopplysninger og opptak av intervju.

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra Oslo Metropolitan University har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- *OsloMet - storbyuniversitetet* ved Kari Skrautvol, mail: kari.skrautvol@oslomet.no, Tlf: 67 23 61 85, mobil: 93 62 13 28.
- Vårt personvernombud: Ingrid S. Jacobsen ved OsloMet. Personvernombudet kan nås via e-post: personvernombud@oslomet.no.
- NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Prosjektansvarlig

Eventuelt student

(Forsker/veileder)

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet 'Pasienters og helsepersonells erfaringer med råd om kosthold, fysisk aktivitet og integrerende helseomsorg ved IBD i tverrfaglig rehabilitering', og har fått anledning til å stille spørsmål. Jeg samtykker til:

å delta i intervju

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, innen 31.12.2024.

(Signert av prosjektdeltaker, dato)