



UiT The Arctic University of Norway

Department of Community Medicine

The self-management work of food hypersensitivity

A study using a population-based cross-sectional study design and qualitative interviews

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A dissertation for the degree of Philosophiae Doctor - August 2019

Acknowledgements

This thesis has been made possible by funding from the Department of Community Medicine, UiT The Arctic University of Norway. Working on this thesis has been an interesting experience, and I am very grateful to all those who have made it possible.

I am sincerely grateful to my main supervisor, Birgit Abelsen, for her considerable work in guiding me through my research education. You are always available and focused, never seem to forget anything, neither details nor the entirety, and are always highly supportive and constructive.

I also want to thank my co-supervisor, Tonje Braaten, who always shared her vast knowledge with me in a very considerate way, and I want to thank my second co-supervisor, Aud Obstfelder, for the highly important and interesting comments, questions, and suggestions.

I want to express my gratitude to the Department of Community Medicine leader team, in particular Anne Fismen and Magritt Brustad, and all my colleagues at the Department of Community Medicine and Centre for Care Research, for making my work day predictable, interesting, and enjoyable.

I could not have completed this thesis without the respondents who participated in the Norwegian Women and Cancer (NOWAC) study and the 16 women who contributed their time to participate in the qualitative interviews. I also want to thank those who helped me recruit interviewees for their valuable contribution.

I want to thank Kristin Benjaminsen Borch for her practical help and useful suggestions, Benedicite Langseth-Eide and Roald Bolle for helpful information, Eiliv Lund for important advice and access to NOWAC study data, and Jan Abel Olsen and the Health Services Research Group for economic support. I also want to acknowledge Trudy Perdrix-Thoma for language review, and Hege Myrvang for transcribing qualitative interviews. I also want to thank Mette Bech Risør, Torun Hamran, Cathrine Arntzen, Bodil Blix and Astrid Gramstad for their constructive comments in the last phase of the writing of this thesis.

My greatest thanks to my friends and family for their considerable support. Finally, I want to thank my two dear sons, Håkon and Vegard, and in particular, I want to thank my wife, Berit, for all her help, and for her love and tremendous support.

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Summary

Food hypersensitivity (FH) is a controversial topic, which has received increased attention in the public, the media, and in the scientific community in recent years. However, despite this focus on FH, little attention has been given to the tasks people undertake to manage their FH. In line with the theoretical framework of this thesis, these tasks are understood as self-management 'work' of FH.

The aim of the present thesis was to explore the characteristics of women with FH, the nature of the self-management work of FH, and what makes women with FH do the self-management work of FH.

The thesis consists of quantitative and a qualitative components, which were carried out sequentially. The quantitative component (Paper 1) was carried out to explore the characteristics of women with FH. Paper 1 was a descriptive epidemiological study with a cross-sectional design and was based on questionnaire data from a random sample of 64,316 women aged 41-76 years. Findings from Paper 1 were used to inform the choice of the sample that was used in the qualitative studies reported in Papers 2 and 3. Qualitative individual interviews were then carried out among women with FH aged 39-67 years in order to explore the nature of the self-management work of FH and what made the women do the self-management work of FH.

Paper 1 showed an association between reporting FH and poor self-perceived health and comorbidities, such as chronic fatigue, depression, and fibromyalgia. The odds of reporting FH increased among women who had more than 9 years of education and those who did not work-full time. Paper 1 showed a 6.8% prevalence of FH in the large representative study sample. In Paper 2, interviewees' descriptions indicated that they carried out a considerable amount of tasks to manage their FH, and that they did most of these tasks themselves. Those who had been able to determine which foods caused negative symptoms could concentrate on implementing a restricted diet, which eventually became routine. However, those who had not been able to determine which foods caused negative symptoms carried out iterative tasks to find out what concrete products to eat, implement tentative restricted diets, and evaluate these diets. Some interviewees described concealing their restricted diet and FH. Paper 3 indicated that the desire to avoid uncomfortable symptoms, the negative consequences of these symptoms, and embarrassing episodes, were strong motivational factors for carrying out a restricted diet as well as the other self-management tasks of FH. Furthermore, access to

certain individual resources, like energy, and to social resources, like acquaintances with knowledge of FH or nutrition, were crucial to identifying which foods caused symptoms and what concrete products and meals to eat. Participants expressed that their FH was often not taken seriously, was perceived as a fad, and was confused with other reasons for having a restricted diet.

The qualitative component of this thesis showed that some interviewees carried out a considerable amount of tasks to manage their FH, which can be interpreted as a large self-management workload. However, the quantitative component showed that a subgroup of women with FH has poor self-perceived health and comorbidities that can lead to a decreased capacity to do the self-management work of FH.

Paper 2 indicated that in particular those who have not been able to determine which food(s) caused symptoms have a large self-management workload. Thus, help from health care services to clarify which foods cause symptoms may not only have the potential to reduce symptoms, but also to reduce the amount of self-management work.

Some women with FH made efforts to conceal their restricted diet and FH. Some possible reasons for this concealment may be related to the fact that people with long-term conditions try to avoid burdening others, that FH is a low status condition, that food and meals represent a 'zone of conflicting views and concerns', and that a restricted diet may disturb the intimacy and bonding a meal can provide and breaks the social rules of the meal.

Sammendrag

Matoverfølsomhet er kontroversielt og har fått mye oppmerksomhet i offentligheten, i media og av forskere de siste årene. Imidlertid har det vært lite fokus på det personer med matoverfølsomhet gjør for å håndtere matoverfølsomhetstilstandene sine. I tråd med denne avhandlingens teoretiske rammeverk forstås det personer gjør for å håndtere sin matoverfølsomhet som 'arbeid'. Målet med denne avhandlingen er å belyse hva som karakteriserer kvinner med matoverfølsomhet, utforske arbeidet med å håndtere matoverfølsomhet, og utforske hva som gjør at kvinner med matoverfølsomhet utfører dette arbeidet.

Problemstillingene ble belyst ved hjelp av både kvantitative og kvalitative forskningsmetoder. En kvantitativ epidemiologisk deskriptiv studie (artikkel 1) ble utført for å belyse hva som karakteriserer kvinner med matoverfølsomhet. Denne studien baserte seg på data fra spørreskjema fra 64 316 kvinner i alderen 41-76 år. Studien viste en sammenheng mellom rapportert matoverfølsomhet og dårlig egenvurdert helse. Det var også en sammenheng mellom matoverfølsomhet og tilstander som kronisk tretthet, depresjon og fibromyalgi. I tillegg fant vi en sammenheng mellom matoverfølsomhet, høy utdanning og det å ikke jobbe fulltid. Studien viste en prevalens av matoverfølsomhet på 6,8 prosent.

Kvalitative semi-strukturerte individuelle intervjuer ble brukt til å utforske arbeidet med å håndtere matoverfølsomhet og hva som gjør at kvinner med matoverfølsomhet utfører dette arbeidet (artikkel 2 og 3). 16 kvinner med matoverfølsomhet i alderen 39 til 67 ble intervjuet for å belyse disse problemstillingene. Kvinner som deltok i de kvalitative intervjuene beskrev at de utførte mange og også tidkrevende aktiviteter for å håndtere matoverfølsomheten, noe som indikerer at det å håndtere en matoverfølsomhet kan medføre en stor arbeidsbyrde. Kvinnenes beskrivelser tyder også på at de utførte mesteparten av arbeidet selv, med lite hjelp fra andre. De som hadde fått avklart hvilke matvarer de ikke tålte, kunne rette oppmerksomheten mot det praktiske arbeidet med å gjennomføre en diett med restriksjoner, og etterhvert gjøre dette til en rutine. De som ikke hadde fått fullt avklart hvilke matvarer som gav symptomer, beskrev derimot at de gjentatte ganger utførte tiltak for å finne ut hvilke konkrete produkter de kunne spise, implementere tentative dietter og evaluere disse diettene, noe som innebar mye arbeid. Dette kan bety at hjelp fra helsevesenet til å avklare hvilke matvarer man ikke tåler kan bidra til å redusere arbeidsmengden knyttet til håndtering av matoverfølsomhetstilstander.

Noen kvinner beskrev også at de skjulte diettrestriksjonene og matoverfølsomheten for andre. En mulig forklaring på dette kan være at kvinnene hadde et ønske om ikke å belaste andre. Det kan også ha sammenheng med at matoverfølsomhetstilstander har lav status, at mat og måltider er et felt preget av uenigheter og bekymringer og at diettrestriksjoner kan innebære et brudd med de sosiale reglene for måltider.

De kvalitative intervjuene viste at ønsket om å unngå ubehagelige symptomer, negative konsekvenser av disse symptomene og pinlige episoder var viktig motivasjon for å gjennomføre diettrestriksjoner samt annet arbeid med å håndtere matoverfølsomheten. Intervjuene indikerte også at håndteringen av matoverfølsomheten i stor grad var avhengig av hvorvidt kvinnene hadde tilgang til relevante individuelle og sosiale ressurser, som for eksempel bekjente med kunnskap om matoverfølsomhet og/eller ernæring.

Den kvalitative delen av avhandlingen indikerer at det å håndtere matoverfølsomhet kan innebære mye arbeid. Den kvantitative delen viser derimot at en undergruppe av kvinner med matoverfølsomhet har dårlig helse, noe som kan redusere kapasiteten deres til å utføre arbeid knyttet til å håndtere matoverfølsomhet.

List of papers

The thesis is based on the following papers, referred in the text as Papers 1, 2, and 3.

Paper 1

Jakobsen MD, Braaten T, Obstfelder A, Abelsen B. Self-Reported Food Hypersensitivity: Prevalence, Characteristics, and Comorbidities in the Norwegian Women and Cancer Study. PLoS ONE. 2016; 11(12):e0168653. doi: 10.1371/journal.pone.0168653.

Paper 2

Jakobsen MD, Obstfelder A, Braaten T, Abelsen B. The self-management work of food hypersensitivity: A qualitative study. Submitted to SAGE Open.

Paper 3

Jakobsen MD, Obstfelder A, Braaten T, Abelsen B. What makes women with food hypersensitivity do self-management work? BMC Health Services Research. 2019; 19(1):462. doi: 10.1186/s12913-019-4243-6.

Abbreviations

BMI	body mass index
CI	confidence intervals
COR theory	Conservation of resources theory
FH	food hypersensitivity
FODMAP	fermentable oligosaccharides, disaccharides, monosaccharides, and polyols
IBS	irritable bowel syndrome
IgE	Immunoglobulin E
NOWAC study	The Norwegian Woman and Cancer study
NPT	Normalization Process Theory
OR	odds ratio
REC	Regional Committees for Medical and Health Research Ethics
TSD	Tjenester for Sensitive Data (Services for Sensitive Data)

1. Introduction

Food hypersensitivity (FH) is a collective term for all adverse (non-toxic) reactions to food(s) and is also referred to as food allergies and food intolerances [1]. FH is a controversial topic which has received considerable attention in the public and in the media in recent years [2]. One important reason for this controversy is the apparent increase in the proportion of people who claim to have FH. This apparent increase causes considerable concern among medical doctors and others [2]. The concern is that if people misinterpret their symptoms to be a result of FH [3], it could lead to unnecessary dietary restrictions, which may require unnecessary effort and have negative social and nutritional consequences [3].

Despite the increased attention in the public, the media, and in the scientific community in recent years [2], research concerning several aspects of FH is still lacking. FH in adults is usually a lasting condition [3], which must be managed every day through carrying out tasks as reading ingredient lists and making double dishes to avoid certain foods [4]. Following the theoretical framework of this thesis, which described the tasks carried out to manage long term-conditions as 'work', I understand the tasks undertaken to manage FH as self-management work of FH. While the self-management work of other conditions has been explored [5, 6], the self-management work of FH has received little attention. Furthermore, less research has been done on adults with FH than on children with FH and their parents, and relatively few studies have explored FH from the perspective of individuals with FH. Therefore, in the present thesis, I aimed to expand our knowledge about the self-management work of women with FH. In order to achieve this, I wanted to explore the nature of the self-management work of FH and what makes women with FH do this work, as described by the women themselves.

Since a central aim of the present thesis is to explore the self-management work of FH, the present study included women who might carry out such work, irrespective of whether or not these women had a conventional medicine-diagnosed FH. Consequently, the term FH in the present thesis refers to both conventional medicine-diagnosed FH, self-diagnosed FH, and 'alternative medicine-diagnosed FH', since all these conditions may involve FH-related self-management work.

I explored the self-management work of adult women with FH through qualitative interviews with women with FH. Polit and Beck [7] and Patton [8] agree that it is important to have a purposeful strategy when choosing a qualitative interview sample. They further emphasized

that if knowledge about the field is lacking or if one is unfamiliar with the field, there are advantages to using typical case sampling, since the data from a typical sample can help the researcher understand basic or key aspects of the phenomenon under study [7, 8]. Patton [8] adds that survey data, demographic data or demographic statistics can be used to select typical participants. However, such data were lacking on women with FH. To compensate for this, in Paper 1 I carried out a descriptive epidemiological study to determine the characteristics of women with FH. The main findings of Paper 1 were used to inform the qualitative interview sample from which data were collected for Papers 2 and 3.

Thus, the three papers in the present thesis were as follows:

Paper 1 examined the characteristics of women with FH using a descriptive epidemiological cross-sectional study design. The sample consisted of 64,316 women aged 41-76 years. Paper 1 also provided valuable knowledge about the prevalence of self-reported FH.

In Paper 2, I carried out qualitative individual interviews with women with FH concerning the nature of the self-management work of FH. This sample consisted of 16 women with FH aged 39-67 years.

In Paper 3, I used the same qualitative interviews as Paper 2, and carried out a qualitative analysis of these interviews to explore what made the interviewees do the self-management work of FH.

1.1. Outline of the thesis

In the following subchapters of Chapter 1, I will first provide an account of FH. Among others, I give an epidemiological and medical description of FH. FH has some similarities with long-term conditions, and former studies on long-term conditions seen from a sociological perspective have the potential to add important perspectives to the present study. Therefore, I will present former studies on long-term conditions seen from a sociological perspective, as well as studies concerning self-management of long-term conditions. Then I will outline the theoretical framework of the present study. This theoretical framework includes perspectives concerning the self-management work of long-term conditions.

In Chapter 2, the rationales and aims of the study are presented. The qualitative interviews gave unpredicted results, which made it necessary to bring additional perspectives into the study, and these perspectives are presented in Chapter 3. In Chapter 4 the study methods are

presented, and in Chapter 5 the methodological considerations are discussed. The results of Papers 1-3 are presented separately in Chapter 6, while the results are reassembled and discussed in Chapter 7. In Chapter 8, the ethical considerations of the project are presented, while Chapter 9 holds the conclusions of the study.

1.2. Food hypersensitivity

In this chapter, I will first give a brief description of the epidemiological research on FH, before I present some FH conditions from a medical point of view. After this, I will give a brief outline of health care services to adults with FH, before I describe how FH conditions are managed.

It is a common perception that a large percentage of the population report that they have FH, and some consider FH to be a fad that mainly affects healthy, middle-class women who are overly concerned with health [9, 10]. However, there are relatively few epidemiological studies on FH in adults, and some of these studies have methodological weaknesses. Thus we know relatively little about the prevalence of FH and the characteristics of adults with FH.

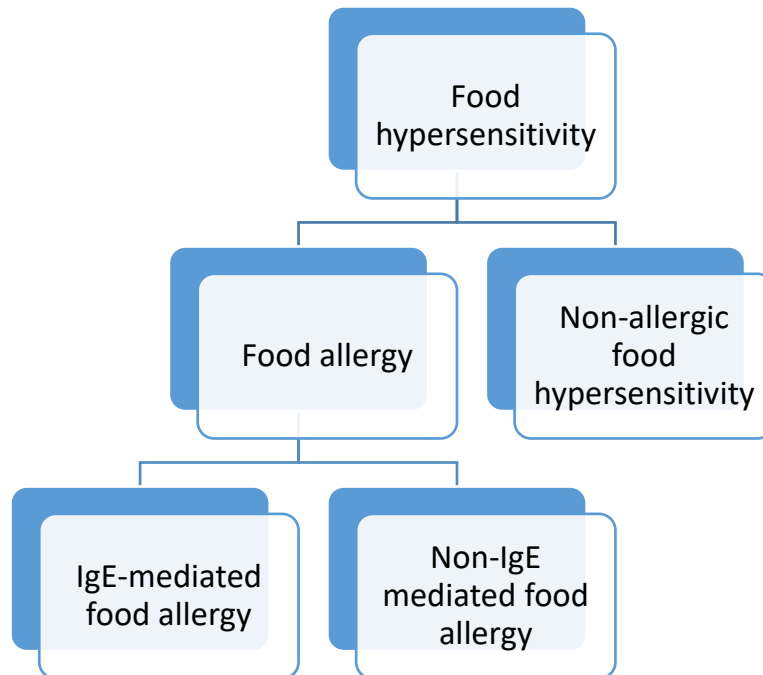
Different studies have reported very different estimates of the prevalence of FH, varying from 3-35% [11, 12], and a review indicated that several of the studies on the prevalence of FH have methodological weaknesses [11]. One of these weaknesses is that the studies' main topics were allergies or related topics, which increases the risk that individuals with FH were overrepresented [11].

When it comes to the characteristics of adults with FH, one study suggested that young women and women with a high education level report FH more often than older women and women with a low education level [13]. A study on food allergies suggested that FH is more often reported among people living in cities than those living in other areas [14]. A paper on people with gluten-free diets indicated that these people have a lower body mass index (BMI) than others [15]. Two studies from clinical settings on people with FH-related symptoms (which could not be explained by medicine despite medical examinations) indicated an association between FH and other long-term conditions, including musculoskeletal pain [16, 17]. Further, a study on celiac disease indicated an association between untreated celiac disease and depression and fatigue [18]. In summary, some epidemiological studies on the topic had weaknesses, most studies were concerned with specific FH diagnoses or subgroups

of individuals with FH, and descriptive epidemiological studies on adults with FH, as defined in the present study, are sparse.

In the medical literature, FH is categorized into food allergy and non-allergic FH; the latter has also been referred to as food intolerance (Figure 1) [1].

Figure 1. Medical nomenclature of food hypersensitivity [1]



IgE: Immunoglobulin E.

A food allergy is an immunological reaction to a given food; eggs, milk, peanuts, tree nuts, fish, wheat, and soy are the most common causes of such reactions [3]. Food allergies can be Immunoglobulin E (IgE)-mediated or non-IgE-mediated, or a mixture of these [1, 19]. IgE-mediated food allergies are the most common, and are the result of a reaction between an allergen, like a food protein, and the antibody IgE [3]. Common food allergy symptoms include gastrointestinal symptoms, respiratory symptoms, skin symptoms, and circulatory symptoms [20].

Some food allergies are relatively easy to diagnose and can be diagnosed based on IgE-tests (blood serum and/or skin prick test) combined with a thorough clinical history [3]. In other cases, the diagnosis is more difficult, and the patient's clinical history and IgE-tests must be supplied with an elimination-reintroduction diet and/or an oral food challenge [3]. In a

diagnostic elimination-reintroduction diet, the food(s) suspected of triggering symptoms is avoided for 2-4 weeks or more and then reintroduced [3, 21]. An oral food challenge means that the patient eats a larger and larger portion of a food, until a possible reaction occurs [21]. The oral food challenge can be carried out blinded or open [21], and the double-blind placebo-controlled food challenge, where neither patient nor health service personnel know whether the placebo or offending food is given, is seen as the gold standard test [20, 22]. People who have been diagnosed with a food allergy are usually advised to avoid the food(s) that causes symptoms [3].

Celiac disease is a permanent intolerance of dietary gluten, and this FH condition can be diagnosed by conventional medicine through serological and histological tests, that is, a blood sample and biopsy [23, 24]. A duodenal biopsy is taken before and after a gluten-free diet is implemented, and this biopsy is considered to be the gold standard test for celiac disease [24]. In people with this disease, ingestion of gluten leads to an immunological reaction which results in inflammation of the small intestine, which in turn leads to villous atrophy and flattening of the mucosa [3, 24, 25]. Common symptoms are diarrhea, malabsorption, and fatigue [3, 25]. Studies indicate that poor compliance with a gluten-free diet may increase the risk of other conditions, such as osteoporosis, and may increase mortality [23, 24, 26]. Therefore, people with celiac disease are advised to carry out a strict gluten-free diet [24, 26]. In order to ensure adequate nourishment, it is also recommended that people with celiac disease receive follow-up care from a dietitian or physician with expertise in the field [24].

Lactose intolerance is an example of non-allergic FH. People with lactose intolerance have a reduced or total inability to digest lactose, a sugar found in milk and dairy products, due to an inadequate amount of the enzyme lactase [3]. Common symptoms include abdominal pain, bloating, and diarrhea [3]. Lactose intolerance can be diagnosed by conventional medicine through a lactose breath test and a gene test, among other methods, but these tests may not identify all people with lactose intolerance [27]. Most people with lactose intolerance can tolerate a daily dose of lactose up to 12 g, and most are advised to ingest the maximum amount of dairy products they can tolerate [27].

Generally, the combination of a thorough clinical history and medical tests is important when medically diagnosing FH [3]. However, while in many cases celiac disease, lactose intolerance, and food allergies can be demonstrated through a combination of clinical history and medical tests, other FH conditions, such as irritable bowel syndrome (IBS) cannot be demonstrated by these methods [3]. Instead, these FH conditions are diagnosed based on

symptoms and the exclusion of other diseases [28-30]. According to Sayuk et al. [31] IBS is a collective term that encompasses different conditions, a single explanation cannot explain all IBS, and different mechanisms can trigger or perpetuate symptoms. Common IBS symptoms include abdominal pain and bloating, and diarrhea and/or constipation [3, 28, 32]. Studies have concluded that IBS can lead to a significant reduction in quality of life, increased work absence, and can place a large burden on partners [33, 34]. Some studies have indicated possible overlap between IBS and other FH conditions, such as food allergies and celiac disease [35, 36]. In recent years, a diet consisting of a low degree of certain carbohydrates, also referred to as a low fermentable oligosaccharides, disaccharides, monosaccharides, and polyols (FODMAP) diet, has been used as a therapeutic approach for IBS [37]. Fecal microbiota transplantation has also been tested as a treatment for people with IBS [38].

Different FH conditions have varying degrees of overlapping symptoms [39], thus diagnosing some FH conditions can be challenging, time-consuming, and resource-consuming [3, 39, 40]. In Norway, general practitioners have the main responsibility for diagnosing FH; however, many general practitioners lack knowledge on FH [3]. According to a FH specialist, Roald Bolle, “There are hardly any other conditions in medicine that are so much the subject for both lack of adequate diagnostics, over diagnosis and under diagnosis as reactions to food” [3:3]. Furthermore, while general practitioners have had the opportunity to refer children who need more complex FH investigations to specialist health care services, there has been no such possibility for adults [40]. The situation has very recently improved: four regional competence centers have been established that have the equipment, competence, and mandate to conduct complex investigations of FH in adult patients [41].

According to Bolle [3], the lack of resources and competence on FH in conventional medicine has contributed to individuals self-diagnosing their FH or seeking help from alternative medicine. However, medical doctors and others are skeptical of both self-diagnosed and alternative medicine-diagnosed FH [3, 9]. As indicated, it seems to be a common perception among medical doctors and in the media that a large part of the population misinterprets their symptoms as FH, and that too many self-diagnose FH [3, 42]. In addition, medical doctors argue that alternative medicine actors use inaccurate tests and advise people to implement comprehensive and unnecessary dietary restrictions based on only one test [3, 9].

FH is managed by finding out which foods cause symptoms and avoiding or reducing the ingestion of these foods [3]. Bolle also emphasized the importance of finding out which foods people with FH can tolerate, in order to avoid unnecessary dietary restrictions and the

associated risk of poor nutrition [3]. Further, studies on children with food allergies indicate that parents need practical information on how to manage the FH in daily life; what meals to serve, how to use an epinephrine auto-injector, to what extent to include the allergen in the environment, and how to ensure adequate nutrition despite the dietary restrictions [43-46].

Studies on people with celiac disease have indicated that some people with FH expend more effort preparing food than those without FH, since some people with celiac disease cook two dishes and bake two loaves of bread, one for their family and one for themselves [47]. Close relatives of people with gluten intolerance also reported that the work of preparing food increased [48]. Studies have also shown that people with celiac disease put a lot of effort into reading ingredient lists before consuming products, and some remain constantly alert in order to avoid gluten [4]. Studies on people with food allergies and celiac disease indicate that some people with FH make an effort to inform friends and family about their FH and ask chefs and others who have prepared meals for them about the ingredients [4, 49]. Further, people with lactose intolerance are usually encouraged to first exclude lactose from the diet, before they gradually and systematically reintroduce lactose to the dose they can tolerate [27, 50]. In summary, there are indications that some people with FH carry out tasks or some degree of self-management work to manage their FH [11, 51, 52].

In recent years, the amount of medically-oriented studies on FH have increased, including research originating from Norwegian research groups [16, 17, 21, 38, 53-58]. There has also been a significant amount of studies on FH and quality of life [59-65], as well as on parents' experiences of having a child with FH and their information needs [44, 66-68]. However, studies on and from the point of view of adults with FH are sparse, and studies explicitly exploring the self-management work of FH are lacking.

1.3 Long-term conditions

FH has some similarities with other long-term conditions, thus literature on long-term conditions can add important perspectives to the present thesis. Therefore I will present former studies and perspectives on long-term conditions in this subchapter.

The Department of Health in the United Kingdom defined a long-term condition as a condition “that cannot currently be cured but can be controlled with the use of medication and/or other therapies” [69:4]. Thus, a long-term condition does not last for days or weeks, but for years, and some self-management work has to be done in order to manage the

condition. Whether FH can be considered a long-term condition is debatable but will not be discussed in this thesis beyond pointing out the fact that FH in adults has some similarities with long-term conditions, such as the duration of the condition [3, 31], and the fact that both individuals with FH and those with long-term conditions have to carry out some self-management work in order to manage their condition.

There is a large amount of studies on long-term conditions, and these studies represent many different perspectives. In this chapter, I will briefly describe former research on long-term conditions seen from a sociological perspective. The reason sociological perspectives were chosen, is that sociology is concerned with how individuals influence and are influenced by interpersonal relationships and societal structures. Thus, sociological perspectives have the potential to provide interpersonal and structural explanations to phenomena and actions.

Sociologists have emphasized that having a health condition generally disrupts everyday activities and routines, like going to work and other commitments [70]. However, while the impact of acute conditions is transitory, the impact of long-term conditions is more profound [70]. These impacts can be physical, practical, and economic, among others [71, 72]. In addition, a long-term condition may have considerable influence on a person's view of their future [72]. While healthy people expect their lives to follow a 'normal' trajectory, with relatively predictable chronological steps, the experience of being diagnosed with a long-term condition may lead to a 'biological shift' and a changed and more pessimistic view of the future [72].

A person's self-image may also be influenced by a long-term condition [71]. Charmaz [71] drew upon a symbolic interactionist perspective; she perceived the self to be developed and maintained through social relations. She wrote that factors such as the restricted lives that follows from a long-term condition, social isolation, and being discredited, can reduce the amount of social interactions and have a negative influence on the social interactions that do take place. This creates fewer opportunities to construct a valued self. Charmaz concluded that a long-term condition can lead to 'the loss of self', that is, people "observe their former self-images crumbling away without the simultaneous development of equally valued new ones" [71:168]. However, she also emphasized that for some, such an illness can lead to self-development and self-discovery [71].

Having a long-term condition may also influence a person's self-esteem and their relationships with others [71]. Charmaz elaborated on this, writing that when it comes to

living with long-term conditions, many people hold ideologies “which reveal residuals of the Protestant Ethic” [71:169]. Within this ethic, people are influenced by the values of independence, hard work, and individual responsibility. Charmaz suggested that, even though people do not necessarily support these values in other areas of life, the values tend to influence aspects of living with a long-term condition. Since independence, hard work, and individual responsibility are important values, dependence on others brings forth self-blame. Charmaz [71] emphasized that nobody wants to become a burden, and that becoming dependent on help from others may cause a loss of dignity. Also Nettleton [70] and Bury [72] argued that people do not want to burden others with their long-term conditions, because independence and self-reliance is important in our culture. Reliance on others may place a strain on relationships, disrupt the normal rules of reciprocity and mutual support in a relationship, and challenge a person’s self-esteem [70, 72].

An increasing amount of studies have focused on individuals that live with long-term conditions that are not explained by conventional medicine, also referred to as medically unexplained symptoms [73-75]. Some of these studies point to the fact that, in the absence of an explanation for the symptoms from conventional medicine, health care providers tend to give psychological explanations to people’s symptoms [73]. Many people with medically unexplained symptoms resist these psychological explanations and undergo a large amount of conventional medical tests to try to obtain a biomedical explanation to their symptoms [73]. In addition, social norms dictate that people should make substantial efforts to improve their health and get better [73, 76, 77], which may include undergoing conventional medical tests to find out the cause of the symptoms [73]. Nettleton [72, 73] added that some people with medically unexplained symptoms recognize that medical knowledge is incomplete, and that conventional medicine will not be able to explain their symptoms; instead they will have to rely on their own knowledge and experiences. However, some of these people find that friends and family expect them to continue to search for a medical explanation to their symptoms [73].

Previous studies have also described other social implications of having a long-term condition [70-72]. Kelly [78] wrote about living with ulcerative colitis, which can include physical symptoms like diarrhea and abdominal pain. The condition can also lead to socially challenging or humiliating situations. Kelly reported that people with ulcerative colitis draw unwanted attention and break social rules because of trips to the bathroom. In addition, lack of control over defecation can lead to mortifying episodes. Involuntary defecation is humiliating,

among other reasons, because control is important, and control over defecation is linked to adulthood and is expected of an adult person. The lack of control or the risk of humiliating episodes can lead to social withdrawal and the avoidance of situations in which humiliating episodes may occur, such as going out to eat or for a drink [78].

Further, having a long-term condition can influence the stories or narratives people tell about themselves [73, 79]. According to Arthur Frank [79], people with long-term conditions present three different types of illness narratives: the restitution narrative, the quest narrative, and the chaos narrative. The restitution narrative is a story about symptoms that appear, seeking help, finding out what causes symptoms, treating the condition, and bringing symptoms under control. The quest narrative represents stories about how an illness contributed to learning, self-awareness, or the ability to help others. Thus, the quest narrative is a narrative about how people gained something from their condition. The last narrative, the chaos narrative, lacks a narrative structure, is confusing, and does not provide a 'plot' [79]. Nettleton described that people with medically unexplained symptoms tend to tell stories that have many of the characteristics of a chaos narrative: stories with no clear beginning and which consist of a chaotic myriad of events [73].

Regardless of whether long-term conditions are explained by conventional medicine, the social consequences of these conditions, or the narratives these conditions cause people to recount, most long-term conditions require some degree of self-management [80], and this will be the topic of the following subchapter.

1.4. Self-management of long-term conditions

For people with long-term conditions, effective self-management is considered to be crucial [80]. Self-management differs from self-care: self-management is understood as strategies and tasks carried out to reduce the impact of a long-term condition on physical health status, while self-care is understood as preventative strategies, i.e., tasks performed by healthy people to remain healthy [80]. Self-management includes (1) coping strategies, that is the ability to cope with the psychosocial consequences of the long-term condition, and (2) the tasks an individual must undertake to control or reduce the impact of a long-term condition on their physical health [80, 81]. These self-management tasks are the main topic of the present thesis, wherein they are referred to as self-management work.

It is generally considered important that people do their self-management work [82-86], both

because this work is seen as crucial to maintain individuals' health [82, 87] and because this self-management work is seen as important to avoid strains on health care services [81].

While effective self-management and carrying out self-management work seem to be beneficial to both the individual and with regard to health care service resources [81, 82, 87], self-management work can also imply a deviance from the norm [70], including for those who adhere to a special diet [88]. While a diagnosis from conventional medicine may offer a biomedical explanation for symptoms and a legitimatization of any necessary self-management work [74, 89], self-diagnosed conditions, alternative medicine-diagnosed conditions or diagnoses that are based on exclusion do not offer the same degree of legitimatization [70, 74, 89]. An earlier study on FH indicated that this also applies to FH [10]. People with FH diagnoses based on conventional medicine tests, such as food allergies, experienced that these diagnoses legitimized their restricted diet. On the other hand, those without such diagnoses reported that they lacked this legitimatization [10].

Although self-management work may imply a deviance from the norm [70], people are still expected to do it [82-86]. This emphasis on self-management of long-term conditions can also be found in political documents on health [90]. Such documents reflect the understanding that it is preferred and expected that the patient and his or her network conduct as much of the self-management work as possible, and health care services should support patients so that they are able to do this work [90].

Some researchers think that the self-management workload can become too large for patients and their network [5, 6, 91-96]. Their perspectives on self-management work represent the theoretical framework of this thesis and are presented in the following subchapter.

1.5. Theoretical framework: Self-management work and the workload-capacity balance

Carl May, Katie Gallacher, and some other researchers described the tasks that people carry out to avoid exacerbation events and to manage their long-term conditions as 'work', and they have been critical of the tendency to impose large and increasing self-management workloads on patients [5, 6, 91-96]. They argue that one important reason why some individuals do not carry out self-management work is that the workload is too large. They argue that this large workload may lead to overwhelmed patients, which in turn causes poor adherence, poor health

outcomes, strains on caregivers, and rising health service costs [5, 6, 91-96]. These researchers use the term ‘burden of treatment’ to describe the workload of health care and the impact this work has on functioning and well-being [92, 94, 97].

May et al. [91] suggested that in order to avoid an overwhelming self-management workload, health care providers should be attentive and ensure the workload does not exceed the person’s capacity to do self-management work. If the workload exceeds the capacity, it is referred to as a ‘workload-capacity imbalance’ [98]. A person’s self-management capacity is defined as the “available abilities and resources a patient can mobilize to address the demands health care and life make” [99:1]. A person’s capacity can be influenced by their access to and ability to mobilize physical resources such as energy and time; mental resources like knowledge and literacy; social resources; and economic resources [98, 99]. Poor health, little energy and depression are factors that can reduce capacity, and poor health is described as both an outcome of lack of capacity to do self-management work, and a factor that decreases capacity [98, 99]. On the other hand, may realization of necessary work and the ability to reframe one’s life in the face of a long-term condition increase capacity [99]. Since people have access to different resources and abilities, they have different degrees of capacity [98, 99].

The workload of managing a long-term condition comes in addition to other work, like occupational work and housework, and thus the total workload may influence one’s capacity to do self-management work [98]. Studies also indicate that people with comorbidities, i.e., more than one long-term condition, experience a larger workload than people with one long-term condition, and thus the risk of becoming overwhelmed by self-management work is higher for people with comorbidities [96].

As mentioned, researchers have argued that the self-management workload must not exceed an individual’s capacity, and in order to contribute to avoid a workload that exceeds one’s capacity, studies have, among other things, described the nature of treatment work [5, 6, 92, 95, 100]. Some of these studies used the Normalization Process Theory (NPT) to describe the nature of self-management work [5, 6]. The NPT explains how management practices are enacted through the interconnection of four core mechanisms: ‘coherence’, ‘collective action’, ‘cognitive participation’, and ‘reflexive monitoring’ [5, 101]. Coherence refers to the effort of learning about the illness, its consequences, and its treatment [5, 6]. Collective action means implementing or carrying out concrete self-management tasks. Cognitive participation includes engagement with others to manage the condition as well as mobilizing support from

others. Reflexive monitoring or appraisal work means altering and evaluating the treatment regimens [5, 6].

As mentioned, the aforementioned literature on the self-management work of long-term conditions is an important part of the theoretical framework of this thesis. However, this literature mainly focused on long-term conditions that can be explained by conventional medicine [5, 6, 86, 91, 97]. Thus, the present study, which examines self-management work among women with and without conventional medicine-based diagnoses of FH, has the potential to contribute new insight concerning self-management work.

2. Rationale and aims of the thesis

In the present thesis, I wanted to explore the nature of the self-management work of FH through qualitative interviews. Polit and Beck [7] and Patton [8] emphasized that researchers who carry out qualitative interviews must pay considerable attention to the choice of the study sample [7, 102]. Malterud [102] agreed with this, and stressed the importance of attaining knowledge about the field or phenomenon of study before the sample is chosen. The way I see it, important knowledge about this field of study (self-management work of FH) includes knowledge about those who might carry out self-management work of FH. Therefore, since descriptive epidemiological studies on adults with FH were sparse, I decided to carry out my own descriptive epidemiological study before I chose the qualitative sample.

In addition, Polit and Beck [7] and Patton [8] argued that when one is unfamiliar with the field, purposive, typical case sampling has advantages. A purposive typical sample can be used to “describe and illustrate what is typical to those unfamiliar with the setting” [8:236]. Therefore I chose to use such a sample in the qualitative component of the present thesis. However, since there are few descriptive epidemiological studies on adults with FH I found it difficult to find information to define the typical characteristics of adults with FH. Therefore, I found it necessary to carry out a descriptive epidemiological study (Paper 1) before I recruited the qualitative sample for Papers 2 and 3.

The descriptive epidemiological study required a large, representative sample, and the sample that was available to me was from the Norwegian Women and Cancer (NOWAC) study. Because of this, I chose to restrict this thesis to women belonging to the same age group, as we cannot rule out that characteristics and/or self-management work may be different

between women and men, and between women belonging to different age groups. Since there were few high-quality studies on the prevalence of FH [11], and since this information could be used give an indication of the share of the population that carries out the self-management work of FH, I included an examination of the prevalence of FH into Paper 1.

The main findings from Paper 1 informed the choice of the qualitative sample recruited for Papers 2 and 3. Paper 1 showed an association between FH, poor health, and comorbidities. Thus, I interpreted comorbidities to be a typical characteristic of women with FH. Based on this finding, and in order to ensure variation in the sample, I included women with and without comorbidities in the qualitative sample.

In addition, as former studies have indicated that a diagnosis based on conventional medicine tests legitimizes deviant behavior and a restricted diet [10, 74], I included participants both with and without a FH diagnosis based on conventional medicine tests.

In Paper 2, I explored the nature of the self-management work of FH by interviewing women with FH. In this process, I observed that, despite a large workload and little support from others, many of the women carried out the self-management work that their condition required. What made the women do this self-management work was explored and described in Paper 3. Studies have indicated that, even though it is considered important that individuals with long-term conditions carry out their self-management work, adherence to such work varies greatly [82-86]. It was my hope that an examination of what made women do the self-management work of FH could be used to illuminate the factors that facilitate and hinder self-management in people with other long-term conditions.

Thus, the aim of the present thesis was to explore the characteristics of women with FH, the nature of the self-management work of FH, and what makes women with FH do the self-management work their condition requires.

The three specific aims of the study were:

- Paper 1: To investigate the prevalence of FH and the characteristics, health, and comorbidities associated with FH in the NOWAC study.
- Paper 2: To explore the nature of the self-management work of FH.
- Paper 3: To explore what makes women with FH carry out the self-management work of FH.

When I started the qualitative interviews, I had four assumptions: (1) In line with former studies [10, 74], I assumed that some participants with a FH diagnosis based on conventional medicine tests would describe that they met understanding from others, while I assumed that this would not be the case for women without a FH diagnosis based on conventional medicine tests. (2) In line with May et al. [91] and Sav et al. [96], I presumed that the management of both FH and comorbidities would imply a large workload. Further, I assumed that the management of FH and comorbidities could be competing priorities. (3) Based on the theoretical framework of this thesis, including among others Shippee et al. [98] and Boehmer et al. [99], it was my presumption that access to individual, social, and economic resources would influence women's self-management work capacity and thus the degree to which they carried out self-management work. (4) Based on a former study of medically unexplained symptoms [73], it was my presumption that participants who had not clarified what (foods) caused their symptoms would carry out a large degree of 'coherence' work to find out what caused symptoms. These four assumptions will later be used as a starting point for the discussion of the findings in the present thesis.

3. Additional perspectives used when exploring and discussing the findings on the self-management work of food hypersensitivity

3.1. The Conservation of resources theory

The qualitative interviews revealed that participants were motivated to carry out the self-management work of FH. This made it necessary to bring further perspectives to the study in order to illuminate and discuss these findings. I decided to include a motivation theory into the study, called the Conservation of resources (COR) theory. This theory addresses what produces motivation, and discusses how resources and external conditions influence our ability to do what we are motivated to do [103-105]. The COR theory was originally formulated to focus on major trauma and stress, but it has also become a significant theory in the field of positive psychology [105].

The basic tenet of the COR theory is that people use available resources to retain, foster, and protect the things they value [103, 104]. The things people value include peace, family, self-preservation, well-being, and a positive sense of self and health [103]. The resources we use

when we protect the things we value can include material resources, personal resources (e.g. skills), and social resources, all of which are strongly intertwined. For example, individual resources like self-esteem, self-efficacy, and optimism are correlated with social support. Hence, individual resources and social support run in ‘packs’, also referred to as ‘resource caravans’ [103]. According to Hobfoll [105] the loss or gain of these resources can trigger negative or positive resource cycles. People who lack or lose resources are more vulnerable to further resource loss, and achievement of new resources can start positive processes that lead to further resource achievement [105].

According to the COR theory, conditions external to the individual influence one’s ability to develop and maintain the things one values. These external conditions are called ‘resource caravan passageways’ [103]. Supportive resource caravan passageways enhance individuals’ resource reservoirs, and thus their ability to develop and maintain what they value. Physical safety, clean water, and good schools are examples of resource caravan passageways that support individuals’ resource reservoirs [103]. Supportive health care services (both systems and practitioners) that mitigate treatment burdens can also be seen as supportive resource caravan passageways [106]. However, resource caravan passageways can also hinder or obstruct peoples’ resource reservoirs, and thus people who struggle to ensure their resources are hindered by conditions beyond their control. Hobfoll [105] also emphasized that people with high socioeconomic status tend to have resource caravan passageways that support their resources reservoirs more effectively than those of people with low socioeconomic status .

While the COR theory has the potential to illuminate what motivates people to do the self-management work of FH, social perspectives on food and the meal can contribute perspectives on what complicates this self-management work, and such perspectives will be presented in the following subchapter.

3.2. Social perspectives on food and the meal

Another central finding in the qualitative component of the study was that the self-management work of FH, and whether this work was carried out, seemed to be influenced by the social meanings of food and the meal. Several researchers have written about this topic; however, I have chosen to refer mainly to the French social scientist Claude Fischler, since he addresses many aspects of the social meanings of food and the meal, and since his texts contribute perspectives which can be used to understand the results of the qualitative

interviews in this thesis. However, in addition to Fischler's perspectives, I also present some perspectives on the disagreements over and concerns about food which have existed in recent years.

According to Claude Fischer, our communal meals are an unmistakable demonstration of the fact that humans are social creatures [107]. He writes that the meal has important social functions [107], and that sharing meals signals intimacy between people [107, 108]. The sharing of meals also fosters and maintains intimacy, and bonding. Fischler writes that eating together bring people together and "preserves, revitalizes, builds up kinship or creates artificial kinship" [107:522]. "Eating the same thing means producing the same flesh and blood, it means symbolically building or rebuilding a common destiny" [109:5]. Since the meal is socially very important, people are skeptical of those who do not join the communal meal but engage in 'solitary eating' [107, 109]. Solitary eating is perceived negatively, and the solitary eater incurs suspicion for excluding himself from communal eating [107, 109]. Furthermore, rejecting food others have served destroys the reciprocity of a relationship [109]. When a host serves a meal, the guest is supposed to honor the host by eating the food served [109].

According to Fischler, food is also central to our sense of identity [110]. Food is reckoned to have an effect on our body, thus to a certain extent, 'we become what we eat.' What we eat is further strongly related to the way we perceive ourselves, and ingesting certain foods includes a hope of becoming what we would like to be. Further, food can be seen as an identity marker, a mark of the membership of a group, as well as a way in which to define differences from other groups [110]. People who do not take part in the meal or follow its rules, risk being disintegrated from the group [109].

Fischler [110] also describes peoples' disgust with food, and how, for example, children can refuse some foods and accept only a limited range of foods. This refusal of food is regarded as childish and implies breaking with the strong moral force in Anglo-Saxon countries that says that adults should eat a variety of foods [10, 110]. There are also other rules related to the meal [110]. One of these rules is that one should not pick at one's food or skeptically investigate it, since this can be seen as an expression of distrust [109, 110].

Recently, other researchers have contributed additional insights concerning the social dimensions of food; they have written about the disagreements and concerns that can be found in relation to food and the meal. Holm [111] wrote that the subject of food and meals are

characterized by a concern that the communal meal is on the decline. Holm interprets the concern about this decline as a symbol of the fear of the decline of the family, which has been a recurring topic for decades [111].

Christensen [112] reported that the term nutrients has become central in the last decades, and the ingestion of nutrients has been linked to health and the avoidance of disease [112].

Concurrently, it is now seen as an individual responsibility to ensure one's health through ingesting healthy foods with the right nutrients [113]. On the other hand, this way of thinking and the focus on nutrients has been criticized [112]: Some say that food only is seen as nutrients linked directly to health, while culture, taste, and tradition are, to a large degree, ignored and forgotten. Further, some people have stated that this extreme view of food as nutrients (nutrients as an ideology), can have a destructive influence on peoples' understanding of and relationship to food [112]. In other words, Christensen [112] presents two opposing views on food: (1) food as closely linked to nutrients and health, and (2) food as culture, taste, pleasure, and tradition. Fournier and Poulain [114] described similar opposing views on food in a recently published paper [114].

Kristensen and Rasmussen [115] described a heated debate concerning food in the Danish media. According to these researchers, many reader's letters criticize the worship of health through food and special diets. According to these readers' letters, peoples' relationship with health tends to be extreme and can assume a religious character, or a form for pseudo religiosity, where the body is celebrated as a sacred temple, where expressions such as salvation and cleansing are used, and where people tell stories of changes in diet that are similarities to those of religious conversion. As indicated, this pseudo religiosity and extreme worship of food and health arouses both indignation and concern, some of which is based on the assumption that this extreme focus on diet and health can lead to poorer health, as exemplified by the eating disorder orthorexia. Further, this worship of health and the body is described as being self-centered. However, Kristensen and Rasmussen argued that immersion in food and health is not self-centeredness, but rather a result of the strong imperative that says that we are obliged to take care of our health, including through food, in order to avoid being a burden to our society and the welfare state [115].

4. Methods

The present study consists of one quantitative paper (Paper 1), which was conducted first, and

two qualitative papers (Papers 2 and 3). The quantitative and qualitative results were presented in separate papers. Paper 1 had a cross-sectional design and was based on questionnaire data from a random sample of 64,316 women. I used the questionnaire data to present the prevalence of FH, to present the descriptive characteristics of women with FH, and to carry out logistic regression analyses.

Papers 2 and 3 were based on data from qualitative, individual, semi-structured interviews with 16 women with FH. In Paper 2, a template analysis was carried out in order to explore the nature of the self-management work of FH. In Paper 3, a data-driven analysis was performed to explore what makes women with FH carry out the self-management work of FH. An overview of the three papers is presented in Table 1, and the research methods of the three papers are elaborated in the following subchapters.

Table 1. Overview of Papers 1-3

Paper	Methods	Focus	Data collection	Participants	Data analysis
1	Quantitative Cross-sectional	Prevalence of FH, characteristics and comorbidities associated with FH.	Questionnaire.	A random sample of 64,316 women.	Descriptive statistics and logistic regression.
2	Qualitative	The nature of the self-management work of FH.	Semi-structured individual interviews.	A non-random/purposive sample of 16 women.	Template analysis.
3	Qualitative	What makes women with FH carry out the self-management work of FH.			Data-driven analysis.

4.1. Paper 1: the quantitative epidemiological description of women with food hypersensitivity

In order to examine the prevalence of FH, and the characteristics and comorbidities associated with FH, I conducted quantitative analyses based on a large representative sample of the adult Norwegian female population using data from the NOWAC study.

4.1.1. The Norwegian Women and Cancer study

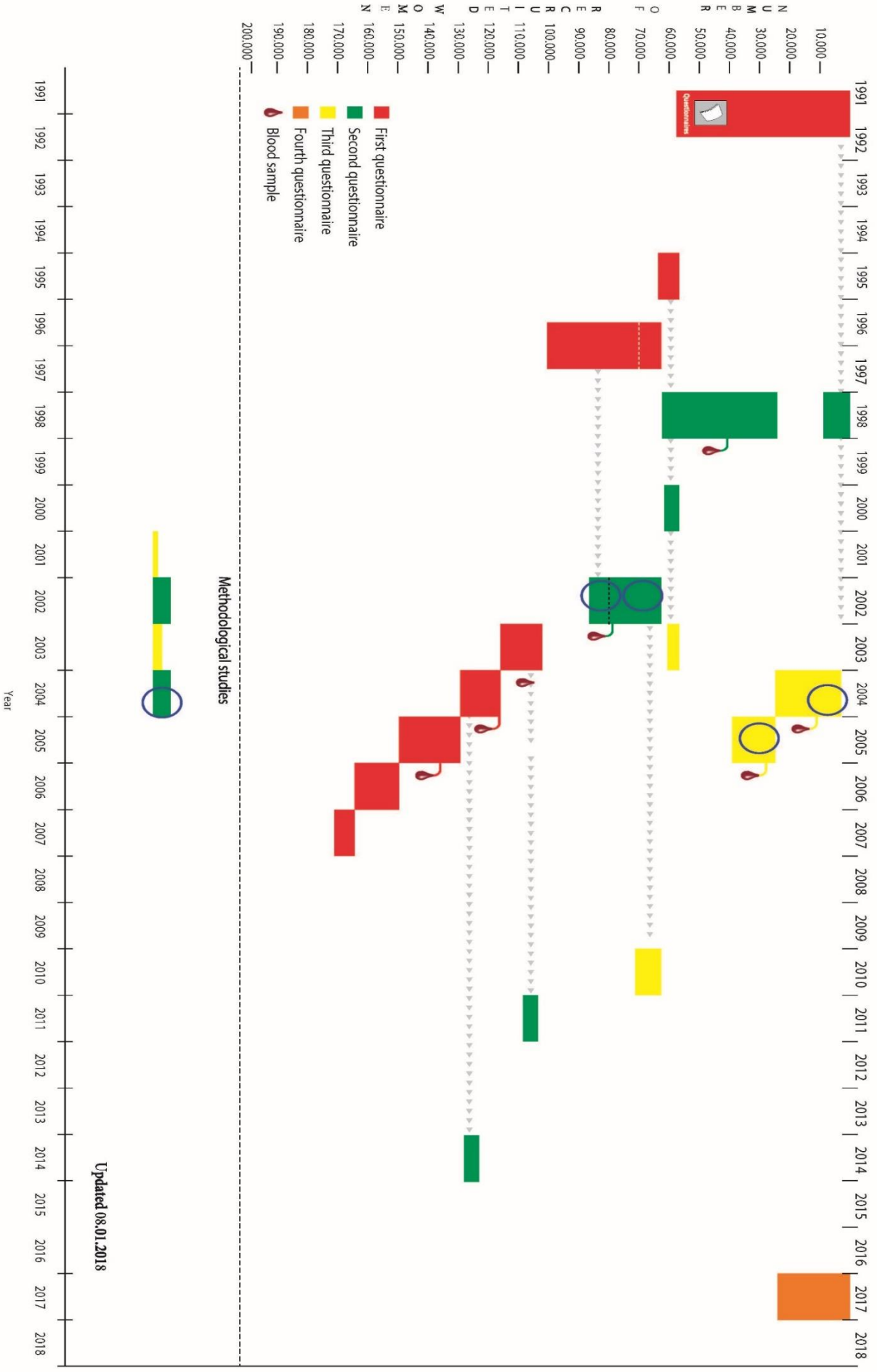
The NOWAC study is a population-based, national prospective study, the rationale and design of which have been described thoroughly elsewhere [116]. The study started in 1991 and was initially established to explore the relationship between external hormones and the risk of female cancers, with a focus on breast cancer [116]. The study has also been used to explore other cancer- and diet-related hypotheses.

Approximately 172,000 women aged 30-70 years at recruitment have participated in the NOWAC study. Most of these women have completed a baseline questionnaire and one or more follow-up questionnaires [116]. The overall response rate in NOWAC is 52.7%. The NOWAC study sample is randomly selected from the Norwegian Central Population Register [116], which contains information about all residents in Norway. An examination of the external validity of the NOWAC cohort revealed no major sources of selection bias, and showed that NOWAC respondents did not differ from the source population, except for a somewhat higher education level [117].

4.1.2. The sample

Questionnaires were mailed to NOWAC participants in 1991-2017; the present thesis included questionnaires completed in 2002-2005 (Figure 2). During the period 2002-2005, 81,065 questionnaires were mailed to potential respondents, of whom 64,316 responded. These participants were 41-76 years, and mean age was 57.1 years.

Figure 2. Enrollment in the Norwegian Women and Cancer study (blue circles represent the study sample for the quantitative component of the present thesis)



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4.1.3. The questionnaires

The questionnaires from which our data were taken were eight pages long. They included questions on self-perceived health status, gross household income, marital status, economic conditions in childhood, reproductive history, smoking status, alcohol consumption, anthropometry, physical activity level, diet, FH, as well as some health conditions [116]. These conditions included depression, muscle pain (myalgia), fibromyalgia/fibrositis, back pain, hypothyroidism, and chronic fatigue. Total duration of education was taken from the baseline questionnaire for all women. The questionnaires varied slightly between mailings, but this variation did not influence our analyses (see Appendix 1 for an example of an information letter and Appendix 2 for an example of a questionnaire).

The question on FH was formulated as follows: “Do any of the following conditions influence your diet?” One of the eight possible response options was “have allergy/intolerance”. I categorized women who ticked “have allergy/intolerance” as having FH, and all others as not having FH. Thus, the FH variable was a dichotomous variable.

4.1.4. The analyses

I conducted the analyses, but the coauthors were actively engaged in discussions of which analyses to perform and the interpretation of the results. I used STATA version 14 in the analyses, and I presented the prevalence of FH as percentages with 95% confidence intervals (CI). Further, I presented the descriptive characteristics of women with and without FH as means or percentages, along with associated p-values based on the Mann-Whitney test or Pearson’s Chi-square test.

I then conducted a first logistic regression analysis to investigate the association between FH and participant characteristics. The dependent variable in this analysis was the dichotomous FH variable, while the independent variables were age, place of residence, duration of education, employment status, self-perceived health status, gross household income, economic conditions in childhood, smoking status, alcohol consumption, BMI, and physical activity level. These independent variables were included in the initial model since previous studies indicated that there might be associations between these variables and FH. However, since gross household income and physical activity level were not associated with FH, these variables were excluded from the analysis. All information except age and place of residence

was self-reported. The specific categorization of the independent variables is described in Paper 1.

In the second logistic regression analysis, I investigated the association between FH and self-reported comorbidities. For this, I included the previously mentioned variables, but replaced self-perceived health status with a variable compounded by the following comorbidities: depression, muscle pain (myalgia), fibromyalgia/fibrositis, back pain, hypothyroidism, and chronic fatigue (see specifics in Paper 1.)

Some of the variables had missing values, and these missing values were managed in two steps. First, I recoded missing answers on questions concerning depression and hypothyroidism to not having these conditions. After this, I conducted multiple imputation, using the chained equations procedure in Stata. The recoding and multiple imputation are more thoroughly described in Paper 1.

4.2. Paper 2: a qualitative exploration of the nature of the self-management work of food hypersensitivity

In order to explore the nature of the self-management work of FH, I carried out qualitative, individual, semi-structured interviews with 16 women with FH. The women were aged 39-67 years, and mean age was 49.7 years. I chose qualitative interviews because of their potential to provide rich information about the lives of the interviewees [118, 119]. I chose to carry out individual interviews since I wanted to explore each woman's individual self-management work. Furthermore, semi-structured interviews seemed to be an appropriate choice, since this approach made it possible to ensure that predefined topics related to self-management work were covered, while leaving the door open to any other topics that the participants might bring forth [118]. I performed all the practical work of recruitment of interviewees and interviewing myself. However, during the recruitment period, interviewing, and analyzing, I was in close dialog with the coauthors. In the following, I will first outline how the sample was recruited, before I describe the sample. Then I describe how data were collected and analyzed.

4.2.1. Participant recruitment

Most of the participants were recruited through contacts in The Norwegian Asthma and Allergy Association, the Norwegian Celiac Association, or through my acquaintances. In addition, I recruited one participant through a respondent invitation on the Norwegian Asthma and Allergy Associations Facebook site, and one participant self-recruited to me when she heard about the topic of the project.

The recruitment procedure was usually as follows: I asked the contacts whether they knew women with FH aged 40 years or more who might want to participate in the study. Then the contacts got in touch with possible interviewees, sent them written information about the project (Appendices 3 and 4), asked whether they wanted to participate, and asked if I could contact them. I chose to use contacts outside the research team because I did not want potential interviewees to feel pressured to participate in the project, and I assumed that a request from someone outside the research team would place less pressure on potential participants than a direct request from the research team.

If the woman wanted to participate, the contact gave me the woman's name, approximate age, and phone number. After this, I called the potential participant. During this phone call, I gave verbal information about the study and clarified the age of the participant. In addition, I clarified whether she had a FH diagnosis based on conventional medicine tests and whether she had comorbidities. Then we scheduled a time and place for the interview. All scheduled interviews were carried out as planned, except one that was cancelled for reasons not related to the project. I recruited a new participant to replace this participant.

Malterud [102] and Polit and Beck [7] emphasized that variation in a purposive qualitative sample is important in order to obtain rich data, and Onwuegbuzie and Leech [120] emphasized that different subgroups may have different experiences; thus inclusion of subgroups helps researchers to “maximize their understanding of phenomena” [120:249]. Therefore, I included subgroups of women with and without a FH diagnosis based on conventional medicine tests, and women with and without comorbidities. My concrete procedure when defining who belonged to which subgroup was as follows: I spoke to the potential participants before the interviews and asked whether their FH was diagnosed by a medical doctor. Based on their answers and on my knowledge about the diagnostic procedures of FH conditions, I categorized them as having or not having a FH diagnosis based on conventional medicine tests. I also asked them whether they had other conditions in addition

to FH that had lasted for months or years. Based on their answers, and on my operationalization of the definition of long-term conditions (i.e., conditions that had lasted at least half a year, which could not currently be cured, but had to be managed/taken into account on a daily basis), I categorized the participants as having or not having comorbidities.

During the last phase of recruitment, I had recruited a sufficient amount of participants with comorbidities, and therefore I asked my contacts to recruit only participants without comorbidities. However, it was somewhat challenging to recruit participants without comorbidities. Therefore, as a pragmatic solution, I recruited one participant who was 39 years old.

4.2.2. The sample

According to Guest et al. [121] 12 participants is usually sufficient in a qualitative sample, since data saturation usually is achieved within the first 12 qualitative interviews, but if the sample is very heterogeneous, a larger sample should be considered [121]. On basis of this, and since the sample in the present study included subgroups and was thus heterogeneous, I decided to include more than 12 participants. On the other hand, Malterud [102] and Sandelowski [122] argued that a qualitative sample should not be too large, since this may contribute to a superficial analysis [102, 122]. Therefore, I included 16 participants in the qualitative sample, and I included an equal amount of participants with and without comorbidities and a FH diagnosis based on conventional medicine tests (Table 2).

Table 2. Number of participants with and without comorbidities and a FH diagnosis based on conventional medicine tests.

	Comorbidities	No comorbidities
FH diagnosis based on conventional medicine tests	4	4
Not FH diagnosis based on conventional medicine tests	4	4

The eight women who had a FH diagnosis from conventional medicine based on tests had celiac disease, food allergies, and/or lactose intolerance. Other selected characteristics are

described in Table 3. Six of the participants had a master's degree, six had a bachelor's degree and four had secondary school as their highest completed education level. This is a high education level compared to the general Norwegian female population [123].

Table 3. Participant characteristics

	FH diagnosis based on conventional medicine tests	Comorbidities	Age
Dina	Yes, Celiac disease	No	39-49
Eline	Yes, Celiac disease	Yes	50-59
Grethe	Yes, Celiac disease	Yes	50-59
Carina	Yes, Celiac disease and lactose intolerance	Yes	60-67
Anna	Yes, Lactose intolerance	Yes	39-49
Helen	Yes, food allergies	No	39-49
Mary	Yes, food allergies	No	39-49
Ruth	Yes, food allergies	No	50-59
Frida	No, possible irritable bowel syndrome	No	50-59
Lena	No, irritable bowel syndrome	No	39-49
Irene	No, possible irritable bowel syndrome	Yes	39-49
Kristina	No, irritable bowel syndrome	Yes	60-67
Sarah	No	No	39-49
Jeanette	No	No	50-59
Nina	No	Yes	50-59
Brita	No	Yes	50-59

Nine participants had minor children, and eight of these participants lived with a partner. Seven participants had adult children, and six of these participants lived with a partner. The interviewees described that they had had FH or symptoms of FH for years or decades. Fourteen participants reported FH to more than one food, and most women reported hypersensitivity to foods that are included in many meals, such as milk, gluten, or wheat.

Some examples of long-term conditions that the interviewees had, which I defined as comorbidities, were: diabetes, hypothyroidism, rheumatism, fibromyalgia, and asthma and allergies that require daily medication. The conditions that I defined as comorbidities were all medically diagnosed. Some conditions that were not categorized as comorbidities were: allergies that did not require ongoing intervention, periodic and undefined musculoskeletal pain, intermediate psoriasis, atopic eczema, and exhaustion/tiredness. One important reason why I defined exhaustion as a symptom and not a comorbidity was that most of the women who mentioned exhaustion described it as a temporary experience that was a result of poorly managed FH. A majority of the women who had comorbidities did not work full-time, and some had a disability benefit or retirement pension. All the women without comorbidities worked full-time.

4.2.3. Data collection

I used the NPT to explore the self-management work of FH carried out by participants. More concretely, I used the NPT to inform the interview guide, and I was particularly influenced by a NPT-informed coding frame developed by Gallacher et al. [5]. The four core constructs in this coding frame are: (1) coherence - work related to understanding the disease and its treatment, (2) collective action - carrying out concrete self-managements tasks in everyday life, (3) cognitive participation - engagement with other people in order to manage the condition, and (4) reflexive monitoring - evaluating and altering the treatment regimen [5]. Accordingly, the interview guide consisted of: (1) coherence - questions regarding how participants found out what caused symptoms and how to manage their FH, (2) collective action - questions concerning concrete self-management tasks such as grocery shopping and preparing meals, (3) cognitive participation - questions concerning possible help from others, eating with others, and how participants informed others about their condition and diet, (4) reflexive monitoring - questions about the evaluation of the management regimen (see Appendix 5 for the interview guide).

As described, the interview guide was influenced by the NPT and by a coding frame developed by Gallacher et al. [5]. However, unlike Gallacher et al.[5], I present ‘collective action’ before ‘cognitive participation’ both in Paper 2 and in this thesis. The reason for this is that, while Gallacher et al. [5] and May [101] emphasized the engagement with and arranging

help from friends, family, and health care providers with regard to the management of long-term conditions, the interviewees described managing their FH to a large degree on their own, with little help from others. In other words, I present cognitive participation after collective action because help from others was not a central topic in the interviews.

The interview guide and my interview technique were tested through a pilot interview, which was not audio recorded. The pilot interview led to minor amendments to the interview guide and somewhat larger amendments to my interview technique to ensure that all interview topics were covered.

All interviews were conducted face-to-face in undisturbed locations chosen by the interviewees, such as interviewees' homes or work place, or on the premises of the UiT The Arctic University of Norway. Only the interviewer and the individual interviewee were present, and the interviews lasted from 53-98 minutes (mean 67 minutes). The interviews were conducted in five different towns in Norway from August until November 2016.

I initiated all interviews by giving information about the study, after which the interviewees signed a written consent form (Appendix 3). Then I started the audio recorder and asked the interviewee to tell me how she found out that there are food(s) she cannot tolerate. Most of the interviewees gave extensive answers to this first question, and I used this information to ask follow-up questions, for example: "You said that [repeating something the participant had said]. Can you say more about this?" A large proportion of the interview was conducted using this procedure, and this led to thorough descriptions of the tasks the women carried out to manage their FH. At the end of the interview, I looked through the interview guide to ensure that all topics had been covered. In other words, the interview guide was mainly used to ensure that all relevant topics were addressed; the preformulated questions in the interview guide were only used to a small degree.

I also asked the participants what help they would have liked to receive from health care services. This question brought forth little information. Typical answers were "What should that be?" and "I just want them to take me seriously". This was clearly in contrast to the questions about their concrete management of their FH, which led to extensive answers.

The first participant interviews revealed findings that led me to adjust the interview guide. Interviewees described receiving little help from family and friends, and thus questions on this topic were removed from the interview guide. Interviewees described little contact with health care services in relation to their FH, mostly because they experienced that health

care services had little or nothing to offer them, as health care services had little knowledge about FH. Therefore the relatively detailed questions about the participants' contact with health care services were also removed and replaced by a question about whether the participants had been in contact with health care services, and a description of this contact.

Another amendment to the interview guide arose after the first interview participants described successful self-management of their FH, even though they described an extensive self-management workload and little support from others. This aroused my curiosity, and after consulting with the coauthors, I decided to try to illuminate the analytical question, 'What is it that makes them manage their FH?' As a result of this focus, I included the question of whether the participants felt they had enough time to do the tasks required to manage their FH into the interview guide. This rather closed-ended question brought forth descriptions of what motivated the women and what hindered the self-management work of FH.

Further amendments to the interviews were related to the fact that some interviewees described concealing their FH. This aroused my curiosity, and I was perceptive of this aspect during the rest of the interviews. In addition, the first interviews showed that tending to small children and occupational work were important competing priorities, which reduced women's capacity to do the self-management work of FH. As a result of this finding, I decided to ask whether the participants lived with a partner, had children, and worked full-time.

The interviews were audio recorded, and shortly after the interviews I transferred the audio file from the audio recorder to the Tjenester for Sensitive Data or Services for Sensitive Data (TSD), which is a secure digital storage service run by the University of Oslo [124]. A professional transcriber then logged on to the TSD, transcribed the audio files to text inside the TSD, and stored these text transcription files in the TSD.

4.2.4. Data analysis

After each interview, I made notes. These included reflections concerning the interview and the interview guide. The notes were discussed with the coauthors, and these discussions resulted in the aforementioned amendments of interviews and the interview guide. In addition, the notes included my immediate reflections and interpretations of the interviewees' descriptions and stories. The writing and discussion of these notes were important elements in the first stage of the analysis.

Template analysis is a thematic analysis method similar to other thematic analysis methods like grounded theory and interpretative phenomenological analysis [125, 126]. However, one important difference between template analysis and other methodologies is that template analysis is not incorporated within a specific methodology and its philosophical assumptions [126]. Thus, template analysis can be used by researchers with several theoretical and epistemological positions, in line with thematic analysis as described by Braun and Clark [126, 127]. Further, according to Brooks et al. [127] a special characteristic of template analysis is that it is a flexible technique which allows the use of a priori themes. In my analysis, I wanted to explore the self-management work of FH in relation to the four predefined core constructs of the NPT, while being open to other aspects of the self-management work of FH and other findings in the data. In addition, I wanted to use an analysis that allowed the present study's theoretical framework. On basis of this, I chose to use template analysis in Paper 2.

The template analysis was conducted as follows: I first read the interview transcripts in order to familiarize myself with the data. Then I made a matrix in which the participants were listed in the rows and the four core constructs of self-management described in the NPT were represented in four columns. As some participants concealed their restricted diet and FH, I interpreted their efforts as 'work of concealing the restricted diet and FH'; thus I added this as a fifth construct of the matrix (Table 4).

Table 4. Template analysis matrix

Core construct	The work of understanding the FH (coherence)	Concrete work to manage the condition (collective action)	Engaging with others (cognitive participation)	Evaluation work (reflexive monitoring)	The work of concealing the restricted diet and FH
Participant 1					
Participant 2					
Participant 3					
Participant 4					
Participant 5					

Etc.					
------	--	--	--	--	--

FH: food hypersensitivity.

Then I listened to all the audiotapes while noting the tasks that participants described carrying out to manage their FH. Each relevant task for each participant was noted in the appropriate cell for the corresponding construct.

After I made this matrix, I read through the transcripts again to verify what I had noted in the cells. Then I looked at the core constructs of the NPT and the work of concealing the restricted diet and FH' one by one, focusing on emerging patterns and variation. Braun and Clark [127] described such focus as an important aspect of thematic analysis. I also examined whether there were any patterns that supported my presumptions (presented in Chapter 2), and I examined the patterns and variation across the core constructs.

Then I created a condensation of the results, which is presented in Paper 2. While writing this condensation, I searched the transcripts to find relevant citations. In both Papers 2 and 3, citations were used in order to illustrate and 'give life to' the text. Usually, I chose the quote that gave the best illustration of the text. However, I also tried to vary which participant was cited.

4.3. Paper 3: a qualitative exploration of what makes women with food hypersensitivity FH do the self-management work of food hypersensitivity

4.3.1. Data analysis and presentation

Paper 3 is based on the same data as Paper 2, and thus the recruitment, sample, and data collection has already been described. However, as mentioned, the first interviews showed that participants, often despite a complex FH condition, a large workload, little involvement from health care services, and little support from others, had found a way to handle, master, or cope with their FH. This piqued my curiosity, and I formulated the analytical question, 'What is it that makes women manage their FH?' I decided to illuminate this analytical question through the interviews.

As described, the analysis of Paper 3 started already in the interview phase. However, the analysis of the completed interviews began with the reading of the interview transcripts, focusing on the new, aforementioned analytical question 'What is it that makes the women

manage the FH?’ I formulated texts that were discussed with the coauthors, and through these discussions, it became clear to me that one important answer to this question was that the women carried out the tasks necessary to manage their FH, in this thesis interpreted as the self-management work of FH. Furthermore, two central reasons why the women carried out the self-management work of FH seemed to be: (1) they had a significant motivation to do the self-management work of FH, and (2) they had the capacity to do the self-management work of FH. Consequently, in the further analysis I focused on these two topics.

The further analysis was as follows: First, I read the interviews searching for what motivated the participants. I found that my question concerning whether they had time to do the self-management tasks of FH had led to descriptions of why they completed these tasks even though they were time-consuming. In addition, as participants described the self-management tasks of FH, they sometimes also gave the reasons why they carried out these tasks, and I interpreted these reasons as motivation. Then, I made a condensation which is presented in the results section of Paper 3. Parallel to the process of making this condensation, I read theories about motivation and coping, and I found that the COR theory and the Self-Determination Theory could be useful when interpreting and discussing the interview results. The Self-Determination Theory was only used in Paper 3, while the COR theory was used both in Paper 3 and in the present thesis.

Secondly, I read the interviews again, focusing on what gave the participants the capacity to do the work of managing FH. Through an iterative process of reading interviews, writing, and discussing with the coauthors, it became clear that individual and social resources, as well as some external factors, were important to the capacity to do the self-management work of FH. The analysis of Paper 3 can be seen as relatively data-driven, but it was also influenced by the COR theory and the Self-Determination Theory [103].

5. Discussion of methodological considerations

In this chapter, I will discuss the methodological choices and possible methodological strengths and weaknesses of the study. First, I discuss the use of both quantitative and qualitative methods in the present study. Then I discuss the methodological considerations of the quantitative component of the study, before I discuss the qualitative component of the study.

5.1. Study design - the use of both quantitative and qualitative methods

In the present thesis, I first carried out a quantitative descriptive epidemiological study and then I carried out qualitative interviews. The main reasons for carrying out the quantitative paper was that I wanted epidemiological knowledge about adults who might carry out the self-management work of FH, as well as information that could be used to choose a typical sample.

According to Creswell [128], one disadvantage of using both quantitative and qualitative methods is that different research practices meet in the same study, and it can be challenging to convince quantitative-oriented researchers about the value of qualitative methods, and vice-versa. In addition, it is my impression that the language used in quantitative and qualitative research differs slightly. This had made the language in this thesis somewhat inconsistent: in the description of the methods and results of Paper 1, the language is more concise than in the description of Paper 2 and 3. In addition, as emphasized by Creswell et al. [128], one disadvantage with using both quantitative and qualitative methods is that it is resource-demanding [128], which has the potential to increase the risk of superficial discussions on either quantitative or qualitative methodology or on study findings.

However, one possible strength of including Paper 1 in this thesis is that, in line with my intentions, it contributed with information about women who might carry out the self-management work of FH, as well as information that could be used to inform the choose of the qualitative sample. In addition, Kerr et al. [9] described that the current debate among in the media cast FH as a ‘epidemic’ and as a largely psychosomatic condition afflicting mainly relatively healthy, middle-class women. Since there have been few epidemiological reports on adult women with FH, one could not determine whether this assertion is correct. However, now Paper 1 contribute with scientific information on this topic, and since it is based on a large representative sample, I argue that Paper 1 has scientific importance and value.

Another strength of using both quantitative and qualitative methods is that the qualitative component of this thesis can be seen in relation to information about women with FH on a population level. For example, the qualitative component of the study indicated that the self-management workload of FH can be considerable, while the quantitative component gave an indication of what share of the adult female population carries out such self-management work.

Even though both qualitative and quantitative methods are used in this study, and results from Papers 1, 2, and 3 are included in the discussion, I do not consider the present thesis to represent a mixed-methods study. The reason for this is that, even though researchers have different definitions of mixed-methods studies [129], there seems to be some degree of consensus that such studies should be understood as those that use both qualitative and quantitative research methods to explore a single phenomenon [128-130]. In contrast, two phenomena are explored in this thesis: (1) the self-management work of FH and (2) the characteristics of women with FH.

However, the literature on mixed-methods has underlined that researchers must use respectively quantitative and qualitative quality criteria to ensure that the quantitative and qualitative components have sufficient quality [131], and this applies to the present thesis as well. In the following subchapters, I first will discuss the methodological considerations of the quantitative component of the study based on quantitative quality criteria, before I discuss the methodological considerations of the qualitative component based on qualitative quality criteria.

5.2. Discussion of methodological considerations in the quantitative component

In Paper 1, I used a cross-sectional study design and a sample from the NOWAC study to examine the prevalence of FH, as well as the characteristics and comorbidities of women with FH. This design has its strengths, but also its weaknesses and possible errors, which can obstruct the study inference.

When discussing strengths, weaknesses, and possible errors of an epidemiological study, it is important to consider the study's internal and external validity [132, 133]. External validity refers to generalizability, and the present study can be said to have external validity if the results can be generalized from the sample to the general female population of the same age span [134]. Internal validity refers to the study's ability to measure what it sets out to

measure, that is whether it actually and accurately measures what it intended to measure [135]. Internal validity can be obstructed by systematic errors (bias), such as selection bias and information bias, and inappropriate statistical modeling, such as not adjusting for important confounding variables [132, 133]. Random errors (chance) may also influence a study, and a large amount of random errors leads to lower precision [133]. In addition, when considering the quality of a study, one may also consider whether the chosen study design is adequate [133], and one should also pay attention to missing values [136].

In the following subchapters I will discuss the strengths and weaknesses of the quantitative component of the study. First I will discuss the study design, statistical methods, and confounding variables. Then I will discuss possible errors and bias, missing data, and external validity.

5.2.1. Design, statistical methods, and confounding variables

As mentioned, Paper 1 used a cross-sectional study design. A cross-sectional study is done on a sample at one point in time or within a short period of time [137], thus the dependent and independent variables are measured at approximately the same time. According to the literature, a cross-sectional study is suitable to measure the prevalence of health conditions and can also be used to investigate the associations between these health conditions and other variables [137]. Thus, a cross-sectional study design had advantages in the present study.

I conducted a logistic regression analysis to investigate the association between FH and participant characteristics, self-perceived health status, and comorbidities. Logistic regression was chosen because the dependent variable was dichotomous, and all data were measured at approximately the same time [138].

A confounding variable is associated with both the dependent variable and one of the independent variables. If the confounding variable is not adequately taken into consideration, the researcher may draw the conclusion that there is an association between the dependent and the independent variable, when this association is actually an effect of the third confounding variable [132, 135]. One way to control and adjust for confounding is by using multivariable techniques and including possible confounding variables into the model [132], and this was done in Paper 1.

All variables identified in former studies that could be associated with FH and were also available in NOWAC study were initially included in the model. However, one cannot exclude that some variables that should have been included in the model were left out. Two health conditions that may be associated with FH according to previous studies are headache and anxiety [17, 55]; however, these variables were not available in the NOWAC study.

5.2.2. Errors and bias

As mentioned, a study can be distorted by both random and systematic errors [135, 139]. Random errors, or chance, are described as variability in data that cannot be easily explained [140]. Random errors can lead to lower precision [133, 140], but this is statistically adjusted for and expressed through the CI [133, 140]. Further, as the sample size increases, the effect of any random errors decreases [140]. Since the sample in Paper 1 was large, the effect of any random error is probably small. Thus, the large sample can be seen as a strength of Paper 1.

Systematic errors, or bias, can distort findings, result in an incorrect estimate of the association between the independent and dependent variables, and undermine the internal validity of a study. Selection bias is one of many possible systematic errors, and selection bias can occur when the sample differs from the source population in such a way that can influence the conclusions [133, 135]. As indicated, selection bias may have been a challenge in former studies of the prevalence of FH, since response rates were low and the surveys' main topics were allergies or related topics [11]. Consequently, people with FH may have been overrepresented among these studies' respondents [11]. Selection bias has also been presented as an important explanation to why estimates of the prevalence of FH from previous studies vary from 3%-35% [11, 12].

The NOWAC study, on the other hand, has a relatively high response rate, and does not focus specifically on FH. Thus, there are no indications that women with FH are overrepresented in Paper 1. Based on this, the sample we used seems a suitable one in which to estimate the prevalence of FH. As indicated, selection bias can influence and reduce external validity [134]; therefore I discuss other possible sources of selection bias in the chapter on external validity.

Another possible systematic error is information bias [133]. Information bias can occur when study participants consciously or unconsciously give incorrect information, or when information is misrecorded for other reasons [133]. One probable source of misrecording is

related to the question on FH (the dependent variable), which was: “Do any of the following conditions influence your diet?”, and one of the possible response options was “have allergy/intolerance”. One cannot rule out that some people with FH did not tick this response because they did not consider that their FH influenced their diet. It is also possible that some did not tick this response because they did not have a conventional medicine-based diagnosis of FH. On the other hand, we cannot exclude the possibility that some people with very marginal adverse reactions to foods ticked this response. In addition, the question was designed in such a way that the respondents had to actively select the option ‘have allergy/intolerance’, without any option listed for ‘not having’ such a condition. This means that both those who do not consider themselves to have FH and those who failed to report their FH were recoded as ‘not FH’. This misclassification may lead to a somewhat underestimated prevalence of FH.

The misclassification that applies to the FH question also applies to other comorbidities included in the logistic regression analysis, such as chronic fatigue and muscle pain (myalgia). This means that both the dichotomous dependent and dichotomous independent variables may contain misclassifications, which may lead to an incorrect estimation of the association between the variables [141]. We assume that this misclassification is non-differential, which means that the misclassification of the independent variable is unrelated to the dependent variable [139, 140]. In our analysis, this means that the misclassification of chronic fatigue or muscle pain (myalgia) is unrelated to whether the respondent had FH or not. Although reservations must be noted, it is usually believed that a non-differential misclassification of dichotomous variables leads to an estimate that reflects the true association but is reduced in magnitude [141, 142]. On basis of this, I assume that the estimation of the association between FH and other comorbidities like chronic fatigue and muscle pain (myalgia) may be somewhat biased; it is most likely that the estimate has the correct direction, but that the odds ratio (OR) is too low.

5.2.3. Missing data

Most survey data have missing values, and in many studies this is addressed by excluding participants with missing data [143]. However, this can lead to a substantial reduction of the study sample, which again can lead to a loss of precision and power [143]. In order to maintain precision and power, I chose to first recode the depression and hypothyroid variable,

and then conduct multiple imputation. One strength of multiple imputation compared to other imputation methods, such as single imputation, is that standard errors are calculated, and uncertainties in predicting the missing values are accounted for [143].

When multiple imputation is conducted, it is important to include enough variables that are predictive of missing values into the imputation model [143]. Therefore, I considered all variables included in the logistic regression analysis, plus number of children, physical activity level, and gross household income. However, it is possible that other variables may also have been predictive of missing values.

In line with what is recommended in studies on multiple imputation, I compared the means of observed and imputed data [143] and found small differences. I also compared results from the logistic regression analysis based on complete-case data with results from the logistic regression analyses based on imputed data, and found small differences (see Appendix S2 in Paper 1 for the logistic regression analysis based on complete-case data).

I did not apply multiple imputation for missing data on the depression and hypothyroid variables. The reason is that multiple imputation can only be conducted when values are missing at random [143], and it is probable that values for the depression and hypothyroid variables were not missing at random, since many who did not answer those questions may have done so because they do not have those conditions. Based on this, the best solution seemed to be to perform ad hoc imputation by recoding missing values to 'no' for the depression and hypothyroid variables. This recoding was in accordance with the other health conditions variables included in the model, where respondents either ticked for having the condition or was coded as not having the condition. However, we cannot rule out that this recoding led to a misclassification of some missing variables to 'no'. This in turn could have led to an incorrect estimation of the association between the variables [141]. Therefore, I decided to investigate the robustness of the estimates by conducting a multiple imputation where also missing variables on the depression and hypothyroid variables were imputed, before I conducted the same logistic regression analysis as in Paper 1 (see Appendix 6). The comparison of the effect estimates from this analysis with the estimates from Paper 1 showed no large differences in ORs. This indicates that the effect estimates are relatively robust, and were not substantially influenced by the recoding of missing values for the depression and hypothyroid variables.

5.2.4. External validity in the NOWAC study

As previously mentioned, external validity in this study means that the results can be generalized from the study sample to the general female population of the same age group [134]. The participants of the NOWAC study are drawn from the general Norwegian female population. Further, the response rate is relatively high, and an examination of the external validity of the NOWAC study concluded that the external validity is high [117]. This indicates that the results of Paper 1 may be generalized to the Norwegian female population aged 41-76 years.

In the examination of external validity, potential differences in demographic characteristics and cancer incidence between the respondents and non-respondents were investigated [117]. The possible differences in regard to general health status and health conditions were not investigated, and other studies have indicated that people with poor health are less likely to participate in surveys than people with good health [144]. However, we have no reason to believe that a potential selection of healthy women would have affected the results of Paper 1.

The examination of external validity looked at the respondents of first mailings [117], and an examination of the possible selection of participants between the first and second mailing showed almost no difference between the participants [116]. Nevertheless, one cannot exclude the possibility that the participants of the first mailing differed slightly from those who also participated in the second and third mailings, which constituted the study sample of the Paper 1. However, again we have no indication that those who dropped out after the first mailing would have answered differently in relation to FH than those who replied to the second and third mailings.

In summary, the large sample, the external validity, and the imputation process can be seen as strengths of Paper 1, while misclassification may have contributed to a somewhat underestimated prevalence of FH and corresponding ORs. The fact that the data are from 2002-2005 may also be a weakness, since the prevalence of FH may have changed in the last years. Finally, the very general FH question can also be seen as a weakness, and future studies should include questions that give more detailed information about the subgroups of FH.

5.3. Discussion of methodological considerations in the qualitative component

While there seems to be some degree of agreement about which quality criteria should be used in epidemiological studies, the same does not apply for qualitative research [131, 145].

This is because qualitative research is a collective term for very different studies, with different methodologies and different epistemological and ontological characteristics [146, 147]. Therefore, Rolfe et al. [146] and Stiege et al. [147] have argued that it is challenging, and not advisable, to use the same quality criteria for all qualitative research.

One way to handle this challenge may be to use quality criteria that are used by researchers who have similar perspectives and/or work within similar research fields. Aksel Tjora is, like me and some of the researchers who have contributed to the theoretical framework used in the present thesis, a sociologist. He works within the field of medical sociology and has written a textbook on qualitative methods [148]. According to Tjora [148] reliability, validity, and generalizability are quality criteria that are often used and are excellent quality criteria in qualitative research. Since Tjora is a sociologist in a similar field, and since I find that the terms he suggests open important methodological discussions, I have chosen to use his terms in the following discussion.

5.3.1. Reliability

According to Tjora [148] reliability reflects the internal logic of a project, and he emphasized that it is important to describe how the researcher and her prior assumptions have influenced the study and its findings. The importance of being sensitive towards how the researcher and her assumptions influence the study has also been stressed by others [102, 145, 149]. Tjora [148] also underlined that the researchers should describe how the choice of participants may have influenced the study findings. Further, the researcher should ensure transparency by describing how the study was carried out, and she should account for other factors internal to the study, such as what information came from participants, what were the interpretations of these findings, how citations were chosen, and how participants were chosen [148]. In the following, I will first discuss how my background, the theoretical framework and the other theoretical perspectives used in the present study may have influenced the study. Then I will discuss how the recruitment method and sample may have influenced the study, before I discuss the transparency of the study.

My decision to focus on the self-management work of FH, and the choice of theoretical framework, may have been influenced to some degree by the fact that, before the study, I observed that the management of FH required some degree of effort or work for some individuals. Nevertheless, as I carried out the interviews, I was often surprised by the large

self-management workload of FH described by interviewees. Further, the theoretical framework may have influenced the choice of research questions, and vice versa. This is in line with Agee [150], who described how the theoretical framework and research questions are inextricably linked. Further, the NPT influenced the interview guide to a large degree, and this in turn affected what data were gathered. As will be elaborated, the use of the NPT in the present thesis also drew attention to the fact that women who carried out a considerable amount of coherence work to find out which food(s) caused symptoms, also carried out iterative self-management work related to the other core constructs of the NPT. This finding may not have become clear to me if the NPT had not been an important part of the theoretical framework of the study. In that regard, the NPT was a useful tool in the present study.

Agee [150] stressed that the theory chosen constitute a lens through which one sees the interviews. Thus, my interpretations of the interviews were influenced by the theoretical framework and the other theory I chose to include in the present thesis. Accordingly, it is possible that the theoretical framework and the use of the NPT made me overlook other topics that appeared in the interviews. This was to some extent remedied by the use of notes, which I wrote after all interviews, and all of which were discussed with the research team. Through these notes and discussions, unanticipated findings were detected, and the study was adjusted in line with these findings. According to qualitative researchers Malterud [102] and Tjora [148], it is important that qualitative researchers be open to unanticipated findings that appear throughout the study.

One of the unanticipated findings we detected was the participants' considerable motivation to do the self-management work of FH, which emerged in the interviews. As a result of this finding, I searched for literature on motivation. The fact that I found and put into use the COR theory may have been influenced by the fact that I am a sociologist. Indeed, the COR theory includes perspectives that can also be found in the field of sociology. For example, the COR theory [103], in line with what is mentioned in an introductory sociology book [151], emphasizes that our ability to do what we want is influenced by available individual and social resources, as well as external factors.

Many participants reported that they carried out a considerable amount of tasks to manage their FH. One obvious explanation for this is that the interview questions were worded and aimed to explore the tasks of managing FH. Another explanation may be related to the fact that many interviewees said they were hypersensitive towards several foods and to foods that are included in many meals. It is possible that the recruitment method, which emphasized

voluntary participation, led to the recruitment of mainly women with relatively complex FH who felt the FH had a considerable influence on their life. I also reflected on whether the patient organizations recruited participants that were particularly afflicted by their FH. However, I did not observe any differences with regard to these factors between participants that were recruited through patient organizations and through my network.

Another aspect of the qualitative sample that has to be taken into consideration is the fact that the sample had a considerably higher education level than the average female population in Norway [123]. Education is considered to be associated with access to resources [105]. This may imply that the sample had access to more individual, social, and economic resources than the average female Norwegian population, including resources that can be used to manage FH. In other words, the sample may have access to more resources that could be used to manage the FH than the ‘average’ woman with FH. Since I aimed to explore what made interviewees do the self-management work of FH, including exploring what resources were used, this was not necessarily problematic. However, if people with a low education level are generally underrepresented in qualitative studies, this may cause individuals with a low education level to become and/or remain ‘invisible’ in research. Further, based on the COR theory [103, 105], if people who have access to many resources are overrepresented in qualitative studies, it may lead to an impression that people with health conditions are more resourceful and more able to do self-management work than the ‘average’ person is.

The importance of transparency in qualitative research has been emphasized by several researchers [102, 145, 148]. In the present thesis, I have tried to attend to transparency, to distinguish between findings and interpretations, and I have accounted for how transcript citations were chosen. However, throughout this thesis work, I have been influenced by the theoretical framework, and this does also reflect how I have understood, interpreted, and presented the interview findings. Among other things, in an early phase I interpreted the tasks participants carried out to manage their FH as the self-management work of FH. This is in particular reflected in Papers 2 and 3, but also in the thesis.

5.3.2. Validity – the interviews and the interview questions

According to Tjora [148], the question of validity is concerned with whether the responses found actually answer the research question posed. A quantitative definition of validity is that it is “the degree to which an instrument measures what it is intended to measure” [7:745]. In

this subchapter, I will reflect on whether my choice of interviews as research method, and the interview questions led to answers of the intended research question.

In order to explore the self-management work of FH, I carried out qualitative individual interviews with women with FH. Tjora [148] criticized the use of interviews when exploring people's practices, and in Paper 2, it is possible that an observational approach could have given better or additional insights into the nature of the self-management work of FH.

However, for Paper 3, qualitative individual interviews seemed to be an appropriate approach, since it seemed able to illuminate motivation and describe the resources participants used when managing their FH. Thus, interviews seem to be more capable of exploring the topics investigated in Paper 3 than an observational approach might have been. Mays and Pope [145] asserted that the combination of two methods should be considered, as it may, in certain situations, improve validity. However, this approach would be more resource-demanding.

During the interviews, I asked the interviewees to give relatively concrete descriptions of the tasks they carried out to manage their FH. This approach revealed rich information on (what I interpreted as) the self-management work of FH, what motivated them to do this work, what resources were used in self-management work, and what external factors influenced this work. However, I also asked participants what help they would possibly have wanted from health care services, and this more abstract, hypothetical question provided little information. This experience is in line with Thagaard, who emphasized that questions concerning concrete topics often give more rich information and result in better interviews than questions with a more general or abstract nature [118]. On basis of this, I would assert that the focus on the concrete tasks of managing FH was advantageous in that it contributed to rich information that illuminated the research questions.

5.3.3. Validity – the sample

As described initially, since I was unfamiliar with the field, I aimed to choose a typical sample, thus I included both participants with and without comorbidities. However, this meant that my sample was only 'typical' with regard to the criteria of comorbidities, and it is unclear to what degree the sample was typical with regard to other criteria.

In the qualitative studies, I aimed to include subgroups, with the intention of contributing to rich descriptions of the self-management work of FH. I also intended to use the subgroups to examine my presumptions (outlined in Chapter 2). However, I did not foresee that the

subgroups of participants would become as heterogeneous and overlapping as they did. For example, many women who I had classified as having a FH diagnosis based on conventional medicine tests mentioned that they also had IBS or other FH conditions that were not diagnosed by conventional medicine. Further, the participants had different comorbidities which may require different degrees of self-management work. In other words, since the subgroups were considerably heterogeneous and overlapping, they were not well suited for examining patterns across subgroups.

Nevertheless, I found that the inclusion of the subgroups increased my awareness of the presumptions I brought to the study. Malterud [102] emphasized that awareness of one's presumptions is important and a resource in qualitative studies. Such attention can keep unconscious presumptions from hindering the knowledge delivered by empirical material [102]. I also experienced that the presumptions, and the fact that these usually were not 'confirmed' by the interviews, increased my focus on the actual findings in the material.

In addition, Malterud [102] and Polit and Beck [7] emphasized the importance of variance in a study sample. As described, participants within and across the subgroups had a considerable variety of FH conditions, as well as overlapping FH conditions and comorbidities. This large variation in diagnoses and comorbidities may have resulted in varied experiences, which may have contributed to rich descriptions of the self-management work of FH and what made the participants do this work. Thus, the choice of study sample may have richly illuminated the research questions, and this may be seen as a strength of the present study.

I included 16 participants in the qualitative sample. As outlined by Patton [8] and Malterud [102], the discussion of sample size in qualitative studies is a difficult one. If one includes too many participants, the analysis may become superficial [102]. On the other hand, if one includes too few participants, some claim that saturation will not be achieved. Saturation is described as the point at which additional data gathering will not add further knowledge [102]. In the analysis of Paper 3, I observed that all the topics were mentioned within the first seven interviews, which is in line with Guest et al. [121], who wrote that most meta themes are usually covered after six interviews. However, sometimes statements in the last interviews made me notice topics that had already been mentioned in the first interviews. This was because the last participants described experiences that contrasted those described in the first interviews, or because the last participants gave more explicit or elaborate descriptions of the topic. On basis of this observation, I find it to be possible that more interviews could have added additional insights to the study. Malterud [102] offered perspectives that I find useful

with regard to the difficult discussion of saturation and sample size. She is critical of the term saturation, and argues that knowledge is always partial and influenced by the researcher.

Based on this [102], I argue that 16 participants represented an acceptable sample size, since more than 16 participants could have led to a more superficial analysis, and the 16 interviews contributed interesting findings which provided partial answers to the research questions.

5.3.4. Validity – analytical methods

In this subchapter, I will discuss the methods of analyses in Papers 2 and 3, and whether the analytical methods were appropriate to provide answers to my research questions. In Paper 2, I wanted to explore the nature of the work of managing FH in relation to the core constructs of the NPT, while being flexible and open to self-management work that was not described in the NPT. Thus, template analysis seemed to be an appropriate method, since it permits both a priori themes as well as themes that emerge from the data [125, 126]. One disadvantage of this structured approach may be that it allows openness to other themes that appear in the data. On the other hand, it was decided before the analysis started that I wanted to explore the nature of the self-management work of FH in relation to the NPT. Thus, the structured approach of template analysis was an effective, to-the-point approach to examine the research questions.

According to Braun and Clarke [127], themes and patterns in data can be identified in two primary ways in thematic analyses: in a theoretical way or in a data-driven way. In Paper 2, data were coded onto a preexisting coding frame, and thus the analysis may be perceived as belonging to the theoretical category. The analysis of Paper 3, on the other hand, was more data-driven. As described, the research question in Paper 3 was chosen as a result of unforeseen findings in the first qualitative interviews, and therefore an analysis that was attentive to what is found in the material seemed to be an adequate approach.

Despite a large degree of openness to the material in the analysis of Paper 3, it is probable that the theoretical framework, as well as other perspectives used in the present thesis, have influenced what I noticed in the material, as well as my interpretations of the findings.

However, as outlined by Tjora [148], it is important for validity that the research project relates to former research, theories, and perspectives. Thus, it can be seen as a strength that Paper 3 relates to former studies, and leans on a theoretical framework as well as other theories.

Malterud and Tjora [102, 148] emphasized the advantages of working in teams when analyzing data. This was done to some degree in the analysis of Papers 2 and 3, since the supervisors read the texts I wrote on based on the raw data. However, if an additional researcher had read the raw data, and the discussions had been based on the raw data, the interpretation of the interviews may have been somewhat different, and the analysis might have been better, or at least different.

5.3.5. Generalizability

According to Tjora [148], generalization in qualitative research is the discussion of whether the findings apply beyond the units that were examined or beyond the setting in which the findings were generated. Tjora is particularly concerned with what he calls ‘conceptual generalization’, which is to find typologies, models, concepts, metaphors, or patterns that do not only apply to the units and settings under examination, but also more generally [148].

The qualitative studies contributed findings that have allowed me to comment on other researchers’ concepts, and in my opinion, this may be seen as a variant of conceptual generalization. For example, I have used the NPT as a tool to explore the self-management work of conditions that are and are not explained by conventional medicine. I found the NPT to be a useful tool when examining the self-management work of both the aforementioned groups. However, I would suggest that the work of handling stigma should be included as an explicit part of the NPT. In addition, when it comes to the concept of capacity, the theoretical framework employed does not take motivation into consideration to a large enough degree. These comments regarding the NPT and the concept of capacity will be elaborated.

In addition to commenting on other researchers’ concepts, and as will be elaborated in the results section, Paper 2 describes four main categories of recognizing which food(s) causes symptoms: (1) through a breakthrough, (2) as an iterative increasing process, (3) as an iterative decreasing process, or (4) as remaining unclarified. I believe that this typology may apply to other conditions as well. In addition, and as will also be elaborated, not clarifying which food(s) causes symptoms may lead to iterative self-management work related to all the core constructs of the NPT. We cannot rule out that also people with other conditions than FH who have not clarified what causes symptoms, carry out work related to many or all core constructs of NPT.

Tjora [148] wrote that ‘conceptual generalization’ includes metaphors that apply to units other

than the ones under study. Later in this text, I present the metaphor 'conflict zone' concerning the subject of food and meals; it may be that this 'conflict zone' of food and meals has some influence over other individuals with special or restricted diets.

6. Results

6.1. Results from Paper 1 – an epidemiological description of women with food hypersensitivity

Paper 1 showed a prevalence of FH of 6.8% among women in the NOWAC study (95% CI: 6.7-7.0). Central findings from the analysis were that FH was associated with poor self-perceived health, with an OR of poor self-perceived health of 2.56. FH was also associated with reporting comorbidities, among others chronic fatigue, depression, and fibromyalgia. The odds of FH increased with the number of comorbidities, with an OR for 5-6 comorbidities of 4.93.

I found a negative association between FH and age (OR 0.97). Women with more than 9 years of education had increased odds of FH, with an OR for 10-12 years duration of education of 1.28. Furthermore, the odds of FH increased among women in the following groups: women who lived in or near urban centers (OR 1.20), women who did not work full-time (OR 1.30), women who had experienced poor economic conditions in childhood (OR 1.20), and women who were not living with a partner (OR 1.26). Women with a low BMI had higher odds of FH than those with a moderate BMI, with an OR for BMI<20 of 1.37. I did not observe a significant association between FH and gross household income.

6.2. Results from Paper 2 – The nature of the self-management work of food hypersensitivity

In qualitative interviews, participants' descriptions indicated that they performed a comprehensive amount of tasks in order to manage the FH, and some of these tasks were time-consuming. Their descriptions also indicated that they carried out most of these tasks themselves, with little help from health care services or their social network. Some of the tasks that they carried out were aimed at trying to find out what caused symptoms, such as contacting health care services, going through different medical tests, contacting alternative clinics, reading books, searching the internet, and eliminating and reintroducing foods. They also expended effort to try to understand the severity of their condition and what concrete meals and products to eat.

Interviewees described carrying out practical activities to implement and attend to their restricted diet, such as making food from scratch and reading ingredient labels. Many participants reported that they spent more time shopping for groceries and preparing food after they implemented a restricted diet compared to before. However, participants who had comorbidities did not describe the tasks of managing the FH and the tasks of managing other long-term conditions as competing, or the sum of the tasks as too large or overwhelming.

People tend to eat together, and the participants described several tasks that they carried out in order to attend to their restricted diet when eating with others, eating meals others had prepared, and in order to communicate to others how to prepare food in accordance with their restricted diet. Some of the concrete tasks they carried out were clarifying the contents of a meal with the chef, asking their husbands to taste food first, bringing their own food, reading ingredient labels on foods other people had bought, picking out the foods they could tolerate, and some observed other people's food preparation.

Based on participants' descriptions, I identified four main categories of recognizing which food(s) caused symptoms: (1) through a breakthrough, (2) as an iterative increasing process, (3) as an iterative decreasing process, or (4) as remaining unclarified. The first category included women who, after a period of poor health, received a FH diagnosis based on conventional medical tests. Participants described this diagnosis as a breakthrough, and expressed that they were glad the medical diagnosis clarified which foods to avoid. Women who described the second category said that they became hypersensitive to new foods from time to time. Thus, from time to time they had to find out which new food caused symptoms and how to avoid this food. Women who described the third category implemented a very restricted diet after experiencing severe symptoms. Later on, they gradually reintroduced foods. The fourth category included women who described an often comprehensive process of finding out to which foods they were hypersensitive, without succeeding.

The first category of recognizing which food(s) caused symptoms implied a complete clarification of which food(s) caused symptoms, and thus an opportunity to move on to the tasks related to implementing a restricted diet, which could eventually become routine. To a small extent, these women evaluated their management plan. However, the other categories, which applied to women who had not clarified which food(s) caused symptoms, implied considerable iterative tasks to identify foods that caused symptoms, which further contributed to the iterative tasks of finding out what concrete products to eat, carrying out a tentative

restricted diet, instructing others in food preparation according to the tentative diet, and repeatedly conducting evaluations.

Participants reported that they were continuously alert in order to avoid food they did not tolerate and that their attention increased when they were eating with others and if their FH was overlooked or forgotten by others. Interviewees also described that their other, non-FH-related, long-term conditions were given attention by the health care services, whereas their FH was often overlooked. They also described that if they had symptoms of both unclarified FH as well as other unclarified conditions, they had to choose which symptoms to discuss with their general practitioner, which could delay the process of clarifying which foods caused symptoms.

The interviews did not confirm my assumption that people with an FH diagnosis based on conventional medicine tests, such as food allergies, lactose intolerance, and celiac disease, were met with more understanding from friends, family, or health care providers than those who lacked such a diagnosis. Instead, participants both with and without a FH diagnosis based on conventional medicine tests said that they were met with both negative and positive reactions; both understanding and lack of understanding.

Irrespective of their diagnosis, some women made efforts to conceal their restricted diet and FH. Some of the reasons they gave for this were not wanting to be the center of attention, the desire not to bother others, the feeling that not being able to eat everything would be associated with weakness or mental disease, and not wanting to be associated with modern diets or with women who are obsessed with food. The women used different strategies when they concealed their FH. Some brought food and tried to eat without being noticed, others searched for something safe to eat without being noticed, while others ate foods they could not tolerate when eating outside the home.

6.3. Results from Paper 3 – What made women with food hypersensitivity do the self-management work of food hypersensitivity

The interviews not only revealed what tasks participants carried out to manage their FH, but also what motivated them to do these tasks, what resources gave them the capacity to do these tasks, as well as which external factors made it easier or more difficult for them to carry out the tasks related to managing FH. In the following, I will outline these findings.

Interviewees reported that the ingestion of certain foods led to uncomfortable symptoms like diarrhea, stomach pain, and nausea, and some interviewees described that these symptoms had led to weight loss. In addition, interviewees described that these uncomfortable symptoms had negative consequences on their lives and made it challenging to do activities that were important to them, such as occupational work and taking care of their family.

Participants also described how symptoms could lead to embarrassing episodes. For example, stomach problems and diarrhea could lead to flatulence and involuntary defecation. Some participants also emphasized the shame related to stomach troubles, referring to it as an unspeakable topic. The wish to avoid these uncomfortable symptoms, and the corresponding negative consequences and embarrassing episodes, were strong motivating forces for the women.

The participants' descriptions indicate that their individual resources and strategies, often in combination with available social resources, were crucial in clarifying which foods caused symptoms, what products and meals to eat, and in carrying out a restricted diet. Important individual resources and strategies were the ability to critically assess advice from others, interest in food, and the realization that it would take time and effort to manage their FH. Those who had a social network that contained people with relevant competence about FH or nutrition described how they took advantage of this. Among other things, advice from others helped participants take less time to find out which foods caused symptoms, and they received advice about how to ensure a nutritious diet despite the restrictions. Correspondingly, participants' descriptions indicated that scarcity of individual and social resources influenced their self-management of FH negatively. For example, participants described that their low energy level meant that they spent a long time finding out what concrete dishes to eat, and led to little variation in dishes.

Participants described tending to children, occupational work, and wanting to take part in meals like everyone else as hindrances to carrying out a restricted diet, as well as to other tasks of managing FH. None of the participants described the economic costs of a restricted diet as a hindrance to its implementation.

When it comes to the external factors that influenced the management of FH, some participants said that they had had symptoms of FH for decades. However, these symptoms had remained unexplained until recently, because FH was not something one thought about in the past. Increased public awareness contributed to the thought that their symptoms could be

FH-related, which for some was confirmed by a conventional medicine-based diagnosis of FH. In addition, participants with FH towards gluten or lactose stated that accessibility to products that did not contain these components had increased in recent years, which made it easier to carry out a restricted diet. On the other hand, some said that the introduction of new foods in the Norwegian diet and an increased tendency to put “everything in everything” complicated the process of finding out whether they could eat a meal or not.

Participants expressed that meals were meant to be shared with others, and that they wanted to take part in meals just like everyone else, and eat what others offered. Some participants said they ate foods they did not tolerate in order to take part in meals. Participants also described that the attention on ‘alternative diets’ had increased the last years, and their FH seemed to get confused with these diets; it was not taken seriously and was perceived to be a fad, and thus some participants found it stigmatizing to carry out a restricted diet. Participants described that this stigma made them conceal their restricted diet and their FH.

7. Discussion of results

FH in adults is usually a lasting condition that cannot be cured but has to be managed, and therefore FH has some similarities with long-term conditions. Paper 2 indicated that women with FH carry out several tasks in order to manage their FH, and as mentioned studies suggest that the tasks that people with long-term conditions carry out in order to manage their conditions can be seen as ‘work’ [5, 6, 91, 95, 101]. On basis of this, I have interpreted the tasks that the women carried out to manage the FH as the self-management work of FH.

I categorized the self-management work of FH in relation to the NPT’s four core constructs: coherence, collective action, cognitive participation, and reflexive monitoring [5]. More specifically, tasks to find out which food(s) caused symptoms and what concrete products and meals to eat was categorized as ‘coherence’ self-management work. Practical tasks in order to carry out the restricted diet were categorized as ‘collective action’ self-management work. The participants’ communication with others with regard to the restricted diet and their efforts to attend to the restricted diet when eating with others were categorized as ‘cognitive participation’ self-management work. Finally, tasks related to evaluating the treatment regimen was categorized as ‘reflexive monitoring’ self-management work.

In the following, I will discuss the main results from the three papers, using literature concerning long-term conditions, self-management work, social perspectives of food, and the COR theory to illuminate and understand the results. I use the four presumptions (presented in Chapter 2) as starting points in the discussions.

7.1. Coherence work - identifying which food(s) cause symptoms

It was my presumption that participants who had not clarified what (foods) caused their symptoms would carry out a large degree of coherence work to find out what caused symptoms. In qualitative interviews, participants who had not clarified which foods caused symptoms gave several descriptions of their considerable efforts to identify these foods. Thus the participants’ answers were in line with my presumption, as well a previous study [73].

Paper 2 showed that participants made efforts to find out what causes their symptoms. Some explanations as to why participants made such efforts were that they wanted to avoid uncomfortable symptoms, the negative consequences these symptoms had on their lives, and embarrassing episodes. Frank [77] and Nettleton [73] also offer perspectives that can

contribute to the understanding of why participants made efforts to find out what caused their symptoms. They argued that patients experience a moral imperative, which demands that they 'be successfully ill' [77] and do what is necessary to get better, including work hard to find out what causes symptoms [73]. Nettleton [73] further argued that in this era, tolerance towards not knowing what causes symptoms is low, and that advances in medical technology decrease our tolerance towards such uncertainty. However, she asserted that medical doctors will not be able to give an explanation or diagnosis based on conventional medicine for all symptoms. In other words, there is a contrast between the demand to find a medical diagnosis for symptoms and the fact that this is not always possible [73].

A central additional finding in Paper 2 was that those who made efforts to identify which foods caused symptoms, also carried out iterative tasks to find out what concrete products to eat, implement tentative restricted diets, instruct others in food preparation according to their tentative diet, and conducted evaluations. This means that those who carried out coherence work to find out what caused symptoms also carried out iterative self-management work related to the other core constructs of the NPT. On the other hand, participants who clarified which food(s) caused symptoms moved on to the practical tasks of carrying out their restricted diet, which became routine. On basis of this, I assume that clarification of which foods cause symptoms has the potential to both remove the coherence work of identifying these foods and reduce the work related to the other core constructs of the NPT.

Previous studies have also suggested that if the self-management workload is reduced, the capacity to attend to other tasks may increase [98, 99]. On basis of this, I assume that help from health care services to clarify what causes symptoms not only has the potential to reduce uncomfortable symptoms, unnecessary dietary restrictions, and reduce the self-management work of FH, but also has the potential to increase capacity, which women with FH can use to carry out other tasks, such as complying with treatment regimens for other conditions. Since Paper 1 showed a prevalence of FH of 6.8%, it may be that less than 6.8 % of adult women will need or want such help. Furthermore, since medical doctors have stated that help from health care services to clarify which food(s) causes symptoms will require a thorough clinical history in combination with medical tests, elimination-reintroduction diets, and/or oral food challenges [3, 40], it seems that such help will usually require one or a few episodes of help.

As described, interviewees in the present study who had not clarified what caused symptoms carried out iterative vacillating coherence work, collective action work, cognitive participation work, and reflexive monitoring work. According to Nettleton [73], people who

have not clarified what causes their symptoms tend to tell ‘chaos narratives’, i.e., chaotic narratives without a start and with a structure that consists of a myriad of events. Seeing the iterative work related to all core constructs of NPT and the chaos narratives in interrelationship, I find it relevant to ask: does carrying out different iterative self-management tasks related to many core constructs of NPT over time have the potential to contribute to chaos narratives? Or, to rephrase this: can the core constructs of the NPT be used as a tool to create some order in chaos narratives?

In summary, women who had not clarified which foods caused symptoms carried out iterative work related to all the core constructs of the NPT, which may imply a relatively large self-management workload. The self-management workload of FH will be the topic of the following subchapter.

7.2. The self-management workload and competing priorities

Before the study, I assumed that the management of both FH and comorbidities would imply a large workload, and that the management of FH and comorbidities could be competing priorities. Indeed, interviewees described carrying out a considerable amount of tasks, some of which were time-consuming, to manage their FH. My interpretation of this is that the self-management workload of FH can be considerable, which is in agreement with studies on (other) long-term conditions [91, 95], including diabetes [152, 153], and celiac disease, which implies comprehensive food preparation work [4, 48]. The 6.8% prevalence of FH reported in Paper 1 gives some indication of the share of adult women who carry out such self-management work. However, my assumption that FH and comorbidities could be competing priorities was not confirmed. One possible explanation is that what I defined as comorbidities were medically diagnosed long-term conditions. According to Jutel [74], medical diagnoses have the potential to provide a more or less clear treatment regimen, and a clear treatment regimen can become routine. Therefore, I assume that many of the comorbidities reported by qualitative interview participants had clear treatment regimens that had become routine, which may have contributed to making the corresponding workload seem manageable.

Another possible explanation for why women with both FH and comorbidities did not describe their workload as particularly large may be that many of them had disability benefits or retirement pensions, and I assume that such benefits and pensions can free up time that can be used to do self-management work. However, the Norwegian welfare state is perceived as

relatively generous with regard to such benefits [154], and therefore we cannot exclude that a study from another country could have yielded other findings.

While comorbidities were not presented as competing priorities to the self-management work of FH, some interviewees described that the tasks of managing FH were not necessarily carried out because tending to small children and occupational work used up the interviewees' time and effort. My interpretation of this is that some participants described occupational work and tending to small children as competing priorities to the self-management work of FH. This finding is in accordance with reports and studies that indicate that Norwegian workers experience high demands in occupational work, and that people give high priority to work and children [155, 156].

Paper 1 showed an association between FH and not working full-time, even after controlling for general health status. This is in accordance with studies that show that people with long-term conditions have lower participation in the labor market than their general health status seem to allow [157]. One possible explanation is that work places are poorly set up to accommodate individuals with long-term conditions [157]. However, based on the above observation that occupational work and self-management work may be competing priorities, I also find it relevant to ask whether a large self-management workload, perhaps in combination with tending to small children, can reduce one's capacity to do occupational work? This speculation is supported by a study that described a time squeeze between self-management work and occupational work [6]. According to political signals, it is considered important that people take part in the work force [158, 159]. The above reasoning begs the question: does a reduction in the self-management workload have the potential to enhance an individual's participation in occupational work?

Paper 2 showed that women with both unclarified FH and symptoms of other unclarified conditions described that they had to prioritize what health complaint to discuss with their general practitioner, and this could delay the diagnostic process of clarifying which foods caused symptoms. One explanation for this is that health care services are more adapted to patients with single health conditions than several concurrent health conditions [90]. In addition, I interpret the clarification of an unclarified FH and symptoms of other conditions as competing priorities. Clarification of a FH may, among other things, require elimination and reintroduction of foods or a food challenge, while clarification of symptoms of other conditions can also require a large effort and will not necessarily lead to complete clarification [73]. Thus, the clarification of a FH and other unclarified conditions may require

a large workload, without necessarily succeeding in clarifying what causes symptoms. Thus it is understandable if some people prioritize the coherence work of clarifying only one condition at a time.

Paper 2 showed that women who had clarified which foods caused symptoms could move on to the tasks related to implementing a restricted diet, which could eventually become routine. My interpretation of this is that the clarification of which foods cause symptoms has the potential to reduce the self-management workload of FH. According to the COR theory [103, 105], individuals with socioeconomic advantages have access to more individual, social, and economic resources that can be used to tend to their health than others. Therefore, I assume that individuals with access to relevant resources have an increased chance of not only tending to their health, but also clarifying what causes symptoms, and thus reduce their self-management workload.

In summary, the presence of symptoms of other unclarified conditions, occupational work, and tending to small children were competing priorities to the self-management work of FH and contributed to a large workload. According to May et al. [91]. and Shippee et al. [98] it is important that the self-management workload does not exceed the capacity a person has available. In the following subchapter, the focus will be on capacity and the factors that influence capacity.

7.3. Self-management work capacity

On basis of Shippee et al. [98] and Boehmer et al. [99], it was my presumption that access to individual, social, and economic resources would influence self-management work capacity and thus the degree to which adults with FH carried out self-management work. The participants' descriptions indicated that individual resources in combination with social resources (such as friends and family with relevant competence about FH or nutrition) were crucial to determining which foods caused symptoms, as well as to other aspects of the self-management work of FH. One important explanation as to why individual and social resources stood out may be that health care services for adults with FH have been characterized by a lack of competence and resources [3, 40]. As health care services have offered little help to adults with FH, there is a larger demand for individual and social resources.

One individual resource that seemed important to the interviewees' self-management work of FH was the ability to critically assess advice from others. In recent years there has been increasing attention on health literacy and its importance in order to tend to one's own health [160]. Health literacy is understood as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [160:95]. Based on the results of Paper 3, I argue that one important aspect of health literacy is whether individuals are able to critically assess health information. This aspect of health literacy may be particularly important when information is complex and contradictory, as is the case with FH [3, 9].

Another central finding in Paper 3 was that many of the interviewees showed considerable motivation to find out what caused their symptoms and to carry out other self-management work. This motivation seemed to play an important role in mobilizing their available resources and carrying out self-management work. The literature on self-management capacity does briefly mention motivation [98, 99, 106]. However, based on the findings of Paper 3, I argue that motivation is an important factor to consider when discussing self-management work capacity.

Participants described experiencing uncomfortable symptoms like stomach pain and nausea, which often appeared a short time after they had ingested adverse food(s), and the wish to avoid these symptoms was an important motivator for doing the self-management work of FH. Other studies have reported that the lack of immediate symptoms reduces the motivation to conduct the work of managing a chronic condition [6, 161]. Thus, the time between self-management work and the occurrence of symptoms may be central to motivation in self-management work. We cannot rule out the possibility that a short time span between self-management work and symptoms is a factor that facilitates self-management work for other conditions as well.

Another aspect that motivated the participants was the wish to avoid involuntary defecation and other embarrassing episodes. This is in line with Kelly's [78] text on ulcerative colitis, which emphasized that several strategies, including withdrawal from certain social situations, are used to avoid embarrassing episodes. Kelly underlined the importance of control to adult people, and she stressed that lack of control represents a potential for considerable humiliation [78]. According to Anthony Giddens [162], many social scientists have written about the importance of control, and Giddens described control of the body as an "inherent part of being a competent social agent". Thus, I assume that the wish to avoid embarrassing episodes may

have a strong motivational potential, and this may also be true for people with other long-term conditions.

Interviewees also said that they carried out their restricted diet in order to stay healthy so that they could carry out occupational work and take care of their family. These statements can be discussed in light of the COR theory. The basic tenet in this theory is that people use their available resources to retain, foster, and protect the things they value [103, 104]. Hobfoll mentioned family, self-preservation, well-being, a positive sense of self, and health as examples of things we value [103, 104]. Thus, individuals who experience that a restricted diet can contribute to better health and an increased capacity to take care of family may be motivated to carry out a restricted diet.

Being influenced by the texts by Charmaz and Burys on long-term conditions [71, 72], I argue that our former self-image and a normal life trajectory may also be counted as things individuals value. However, while Charmaz and Bury described long-term conditions that imply little hope of regaining one's former self-image or a normal life trajectory [71, 72], with FH, there may be hope of becoming completely healthy (again), which may increase one's motivation to do the self-management work of FH.

Some participants described that the public awareness of FH had increased, as had the availability of gluten-free and lactose-free products had increased, which made the process of identifying which foods caused symptoms and the process of avoiding certain foods easier. On the other hand, some participants described an increased tendency to put all kinds of foods in dishes, which made it more challenging to find out which food(s) were included. In addition, participants described an increased public focus on alternative diets, and expressed that their FH tended to get confused with these. This contributed to negative reactions from others and caused some participants to conceal their FH. Thus, factors external to the participants and their close social networks influenced the process of finding out which foods caused symptoms and the avoidance of certain products. This is in line with the COR theory, which takes into account the perspective that factors external to the individual and to her control can influence her attempts to tend to her health [105]. Hobfoll emphasized the influence of external conditions, such as clean water and physical safety [105]. However, based on the present thesis, I argue that external factors like access to relevant products, 'food preparation fashions', and attitudes may also influence people's capacity to carry out the self-management work of FH.

As mentioned in the discussion of methodological considerations, the qualitative sample in the present thesis had a considerably higher education level than the average Norwegian female population [123]. A high education level is to some degree associated with access to resources, and according to the COR theory, individuals who have access to individual, social, and economic resources are more able to hinder resource loss and tend to their health than people with little access to resources [105]. Thus, we cannot rule out the possibility that the qualitative sample had access to more resources that could be used in the self-management work of FH than the general population of women with FH. One finding that could be interpreted as underscoring this assumption, is that none of the participants explicitly said that their economic conditions hindered them from implementing a special diet, while previous studies on people with low-income have shown that financial barriers can be a hindrance to health-related dietary changes [6].

Some qualitative interview participants expressed that fatigue or a low energy level led to little variation in the dishes they ate, and also caused them to spend more time determining what concrete dishes to eat. My interpretation of this is that a decreased energy level reduces one's capacity to do the self-management work of FH, which is in line with earlier studies [98, 99]. The importance of energy is also stressed in the COR theory, which emphasizes that a lack of energy can lead to further resource loss [105]. In addition, according to Paper 1, there is an association between FH and chronic fatigue, which means that a subgroup of women with FH have low energy or fatigue. Paper 1 also showed an association between FH, self-perceived health and depression, and previous studies suggested that poor health and depression reduce one's capacity to carry out self-management work [98, 99]. This suggests that a subgroup of women with FH in the general population may have reduced energy and capacity to do the self-management work of FH. This is in contrast to the observation that FH can cause a large self-management workload.

In summary, Paper 3 indicated that individual and social resources, motivation, and external factors influenced interviewees' capacity to do the self-management work of FH. Other results of Papers 2 and 3 were that women with FH experienced negative reactions towards their FH and concealed their restricted diet and FH. It is difficult to approximate to what degree negative reactions influence self-management capacity or the share of capacity that is used on concealment. However, other aspects of negative reactions and concealment will be discussed in the following subchapter.

7.4. Negative reactions, stigma, and concealment of restricted diet

In this subchapter, I will first briefly discuss my fourth presumption and why it was not confirmed, before I discuss what instead appeared in the material. In particular, I will try to illuminate and discuss possible reasons for the negative reactions to the restricted diets and for concealing the restricted diet and FH. In the last paragraphs, I argue that such concealment can be seen as ‘work’.

My fourth assumption was that some of the women with a FH diagnosis based on conventional medicine tests would describe that their FH was met with understanding from other people, while I assumed that this would not be the case for women who lacked such a diagnosis. However, the qualitative interviews did not support this assumption. Instead, both women with and without a FH diagnosis based on conventional medicine test described both understanding and lack of understanding from friends, family, and health care providers. One possible reason why the above assumption was not supported may be that many of the interviewees with a FH diagnosis based on conventional medicine tests also had other FH conditions which had not been diagnosed by conventional medicine.

Instead of the expected findings with regard to diagnosis, other findings appeared in the material. Participants reported that others confused the restricted diet they followed to manage their FH with other reasons for having a special diet, that their FH were not taken seriously and was perceived as a fad, and that their FH was seen as a weakness or mental disease. Further, they wanted to avoid being the center of attention during meals, and some concealed their FH in order to avoid the stigma of revealing their restricted diet and FH.

Claude Fischler’s texts may contribute to an increased understanding about why people who carry out a restricted diet are met with negative reactions and stigma. Fischler [107] described the meal as socially important, and he emphasized that eating together creates and maintains social intimacy and social bonds. Based on this, I assume that not sharing meals may threaten or spoil the communal meal, the intimacy, and the bonding; therefore not sharing meals has the potential to evoke disappointment or other negative reactions from others.

Fischler [110] also emphasized that people use diet and certain foods to mark their membership to a group and their otherness to other groups. Therefore, I assume that in some cases, and perhaps unconsciously, a restricted diet can be experienced as a rejection of an individual or group. Fischler [110] also stated that ‘precautionary examinations’ of food are seen as unacceptable in our Western cultures; they are seen as childish and is perceived as an

expression of distrust. Furthermore, he emphasized the importance of reciprocity with regard to food and the meal [109]. When a host offers a meal, the guest is supposed to appreciate that meal [109]. It is possible that the above-mentioned factors have the potential to evoke disappointment, anger, and a lack of understanding towards a restricted diet.

I previously mentioned factors that may increase one's motivation to do self-management work, such as the wish to avoid uncomfortable symptoms, embarrassing episodes, and to tend to the things one values. Here, however, I have discussed how a restricted diet may threaten intimacy and can be seen as a rejection. Thus, people with FH may experience both motivation and demotivation to carry out a restricted diet. This is in line with Nettleton's description of some patients with long-term conditions who conscientiously carry out self-management work, while other patients follow a 'social logic' and skip self-management work [70].

Paper 2 showed that some women conceal their FH in order to avoid calling attention to their diet, and thus ensure that their FH is not confused with modern diets and women who are obsessed with food. Studies indicate that in recent years, an increasing number of people have implemented a special diet [163], and this has raised many discussions and considerable concern [112, 115]. On the one hand, there is a large focus on nutrients and their role in maintaining one's health [112]. It has become an obligation to take care of one's health and prevent diseases, which is also done through consumption of the 'right' foods [113]. On the other hand, these trends have been criticized as contributing to the weakening of the culture, taste, and traditions of food, which should not be forgotten [112]. Further, some are concerned that the practice of the communal meal is in decline [111]. According to Holm [111], this concern may be a symbol of another concern: the concern that the family is in decline, which has been a recurrent topic in the last decades. Furthermore, some are concerned that a large focus on nutrients and diets may have a negative influence on health [112], and some are concerned that the preoccupation with diets is assuming an extreme, quasi-religious character [115]. In summary, there are several disagreements and concerns in the public and in the literature pertaining food and the meal. According to our interviewees, FH is often confused for some more criticized diet regiments. Therefore, I argue that food and the meal can be described as a 'zone of conflicting views and concerns', in which people with FH more or less involuntary reside. Further, I assume that some conceal their restricted diet and FH in order to avoid being embroiled in this conflict zone.

Paper 2 indicated that some women concealed their FH because they did not want to bother others with their restrictions. Further, the women described carrying out the vast majority of the FH self-management work themselves. This tendency to carry out the self-management work of FH alone, without revealing their restricted diet, may to some degree be related to the fact that food, the meal, and health are generally the responsibilities of women [164, 165]. However, it is also in line with Charmaz [71], who wrote that individuals with long-term conditions are influenced by the Protestant Ethic and its values of independence, hard work, and individual responsibility, as well as other studies that suggest it is important for many people with long-term conditions not to impose work on or become a burden to others [70, 72]. Furthermore, Bury [72:169] stressed that dependence on help from others “disrupt[s] the rules of reciprocity and mutual support”. Therefore, I interpret the concealment of restricted diets and carrying out the self-management work of FH alone as a way to avoid becoming a burden and to maintain reciprocity and equilibrium in one’s relationship with others.

Some participants mentioned not wanting to be associated with weakness as a reason for concealing their FH. One possible interpretation of this is that revealing a FH implies revealing a long-term condition, which may be associated with weakness. Earlier studies have suggested that revealing a long-term health condition spoils one’s identity as healthy, that being healthy is linked to normality, and that breaking with this normality leads to stigma [70:85, 88, 166, 167].

Album and Westin’s [167] literature on the prestige hierarchy of medical specialties, may also offer a possible explanation as to why people conceal their FH. According to Album and Westin, typical characteristics of a low status condition are: there is no cure for the condition, it is long-term, it affects more women than men, and does not affect any vital organs in the upper part of the body [167]. All of these characteristics apply for FH.

Our qualitative interview participants described several strategies for concealing their restricted diet and FH. Based on this, and on the fact that Malterud and Bjorkman [168] describe concealment as work, I argue that this concealment can be interpreted as work. Malterud and Bjorkman [168] suggest that this work is not done all at once; instead, it is done over and over again, each time the individual is in a new context and meets new people [168]. This is supported by Clair [169], who also described concealment as one of two main strategies of handling stigma, whereas revealing is the other main strategy. In addition, Clair [169] argued people who reveal and conceal will continuously have to choose what concrete strategy to employ. For example, a person who reveals can try to ‘normalize’ their condition

by attempting to make their difference from others seem commonplace or ordinary. Another strategy is to 'differentiate', i.e., to highlight the difference and how it differentiates them from others [169]. Thus, even though the work of concealment was most perceptible in the qualitative interviews, it is probable that the interviewees also had to do the work of revealing when they met new people. We eat several times a day, and thus the work of revealing and concealing may have to be done relatively often.

8. Ethical considerations in the project

Before the project started, and in accordance with the Regional Committees for medical and health research ethics' (REC) procedures, I sent a Remit Assessment form to REC north. REC north responded that this project did not require its approval (reference number: 2014/1565/REC north). After this, the Norwegian Centre for Research Data was notified of the project (project number: 40138), in accordance with their procedures.

All NOWAC participants included in the quantitative component of the study gave written informed consent, and the REC and the Norwegian Data Inspectorate have approved the NOWAC study. The letter of invitation and information about the NOWAC study can be found in Appendix 1.

The participants in the qualitative component of the study also signed an informed consent form before the interviews started (Appendix 3). As mentioned, two of the qualitative interview participants self-recruited, while the rest of the participants were recruited through contacts outside the research team. This recruitment strategy was chosen to prevent potential interviewees from feeling pressured to participate, under the assumption that a request from a third person would place less pressure on potential interviewees to participate than a direct request from the research team. This recruitment strategy was also recommended by The Norwegian Centre for Research Data.

I made sure to maintain the participants' anonymity and confidentiality throughout the study. Among other methods, this was done by storing participants' contact information and consent forms in a locked safe. Further, shortly after a qualitative interview was completed, I transferred the audio files directly from the audio recorder to the TSD, a secure digital storage service run by the University of Oslo [124]. I then deleted the audio files from the audio recorder. When I was not using the audio recorder to carry out interviews, it was kept in a locked closet.

The audio files and transcribed files were only stored inside the TSD throughout the study. Interviews were transcribed inside the TSD, and all qualitative analyses were also carried out inside the TSD. These procedures for storing information and data are in accordance with current regulations.

9. Conclusions and further perspectives

9.1. Conclusions

FH is controversial and has received a lot of attention. However, scientific research on adults with FH and their self-management work has its shortcomings. Therefore, I aimed to explore the characteristics of women with FH, the nature of the self-management work of FH, and what makes women with FH do the self-management work of FH. In order to explore these topics, I first carried out the descriptive epidemiological study reported in Paper 1. Then I conducted qualitative individual interviews with 16 women with FH, the results of which are reported in Papers 2 and 3. One important finding in Paper 1 was that FH is associated with poor health and comorbidities. This finding was used when selecting the qualitative sample for Papers 2 and 3.

Paper 1 showed a prevalence of FH of 6.8%; however misclassification may have contributed to an underestimation of the prevalence. Paper 2 indicated that many interviewees carried out considerable self-management work to manage their FH, and they mainly did this work themselves. On the other hand, the quantitative component of the study showed an association between FH, poor self-perceived health, chronic fatigue, and depression, which may reduce the capacity to do such self-management work.

Women who found out which foods caused symptoms were able to concentrate on the work of implementing a restricted diet, which could eventually become routine, while women who did not clarify once and for all which food(s) caused symptoms continued to do the coherence work of finding out which food(s) caused symptoms. In addition, the use of the NPT in the present study called attention to the fact that those who continued to do this coherence work also carried out the iterative work of implementing a tentative diet, instructing others in the tentative diet, and evaluating the tentative diet. I assume that such iterative self-management work on so many levels occupies a considerable amount of a person's work capacity, and that help from health care services to clarify what (foods) causes symptoms have the potential to free up capacity, which can then be used to carry out other tasks.

Women with FH reported making efforts to conceal their restricted diet and their FH, and I interpreted this as work of concealing. Possible reasons for this concealment are related to the fact that food and the meal is a zone of conflicting views and concerns. In addition, a restricted diet may break with the rules of the meal and threaten the intimacy and bonding a meal can provide. Another possible reason for concealment work may be that FH has the

characteristics of low status condition. Furthermore, the concealment of a restricted diet may be a result of the Protestant Ethic and corresponding values of independence that instruct people with long-term conditions not to impose work on others.

Important reasons why the women carried out the self-management work of FH were that they were motivated and had access to relevant individual and social resources. Examples of individual resources included interest in food and the ability to critically assess advice from others. Examples of social resources were family or friends who had special competences with regard to FH and nutrition. The wish to avoid uncomfortable symptoms and embarrassing episodes, the wish to be able to carry out occupational work and tend to family were important motivators. The interviews also showed that external conditions, like access to gluten-free and lactose-free products, influenced the self-management work of FH. On the other hand, unclarified symptoms of other conditions, responsibility for small children, and occupational work were competing priorities to the self-management work of FH.

9.2. Further perspectives and further research

In the present thesis, I used the NPT as a tool to explore the self-management work of FH. I found the NPT to be a useful tool, which perhaps can be used to explore the work carried out to manage other conditions, both those that can and cannot be explained by conventional medicine. However, while the results of the present thesis indicate that dealing with stigmatization is an important part of the management of FH, stigmatization has only been briefly mentioned in studies concerning the NPT [92, 94]. Since having a long-term condition like diabetes can also be stigmatizing [70, 170, 171], I argue that the work of handling stigma should be added to the NPT, either as a fifth core construct, or as a distinct subcategory of ‘cognitive participation’.

The theoretical framework of the present study emphasized that self-management work capacity is influenced by aspects like access to resources [91, 98, 99]. However, based on the results of the present thesis, I argue that self-management capacity is also influenced by motivation and external factors. These are topics that are discussed in the COR theory [103, 105], which added useful perspectives to the present thesis.

As described in the introduction, epidemiological knowledge on FH has its shortcomings. Paper 1 gave an estimation of the overall prevalence of self-reported FH. However, studies of prevalence of some subgroups of FH, such as food allergies, have weaknesses [11, 51], and

high-quality prevalence studies are needed [11]. Further, it is a common perception that self-reported FH is increasing [2], but since studies on prevalence have weaknesses [11], new studies are needed in order to know whether the prevalence of subgroups of FH are in fact increasing. As described in the methods section, several of our qualitative interview participants with a FH diagnosis based on conventional medicine tests also had IBS or FH conditions that were not diagnosed by conventional medicine. This raises questions about how many women with FH have a complex FH condition, and how many of those with a conventional medicine-based diagnosis of FH also have other FH conditions that have not been diagnosed by conventional medicine.

The quantitative component of the study showed an association between FH and not working full-time, even after controlling for general health status. Further, the qualitative component of the study indicated that occupational work was a competing priority to the self-management work of FH. This caused me to ask the question: could the self-management work of long-term conditions reduce the capacity to carry out occupational work, and could a reduction of self-management work increase one's capacity to do occupational work? These are interesting questions that may deserve further investigation.

The quantitative component of the study showed an association between FH and low BMI, and the qualitative interview participants described symptoms like diarrhea, nausea, and weight loss. Thus, the present study brings forth questions about the nutritional status of women with FH. Studies on children have indicated that restricted diets can lead to insufficient nutrition if the diet is not appropriately supplemented [172-176]. To my knowledge, there are few studies on the nutritional status of adults with FH or on adults with complex FH conditions. Studies also indicate that, in general, older adults have an increased risk of malnutrition [177, 178]. However, we know little about FH in older adults and whether FH increases the risk of malnutrition among other adults. Further research is required to increase our knowledge on these topics.

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RESEARCH ARTICLE

Self-Reported Food Hypersensitivity: Prevalence, Characteristics, and Comorbidities in the Norwegian Women and Cancer Study

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OPEN ACCESS

Citation: Jakobsen MD, Braaten T, Obstfelder A, Abelsen B (2016) Self-Reported Food Hypersensitivity: Prevalence, Characteristics, and Comorbidities in the Norwegian Women and Cancer Study. PLoS ONE 11(12): e0168653. doi:10.1371/journal.pone.0168653

Editor: Andrea S. Wiley, Indiana University Bloomington, UNITED STATES

Received: August 26, 2016

Accepted: December 4, 2016

Published: December 16, 2016

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Data Availability Statement: Data is owned by the The Norwegian Women and Cancer Study (NOWAC). Interested researchers may contact project administrator Eiliv Lund (eiliv.lund@uit.no) for access.

Funding: MJ was supported by the Department of Community Medicine, UiT, The Arctic University of Norway, grant agreement 4025. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Abstract

Background

This study aims to investigate the prevalence of self-reported food hypersensitivity, (SFH), the characteristics of women with SFH, and whether SFH is associated with multiple health complaints among the participants of the Norwegian Women and Cancer study (NOWAC).

Methods

We conducted a cross-sectional study among 64,316 women aged 41–76 years. The women were randomly selected from the Norwegian Central Person Register. Information on SFH and all covariates except age and place of residence was collected by questionnaires in 2002–2005.

Results

The prevalence of SFH in our study sample was 6.8% (95% confidence interval: 6.7–7.0). Logistic regression analysis showed a negative association between SFH and age (odds ratio [OR] 0.97). The odds of SFH increased among women living in or near urban centers, women with more than 9 years of education, women who did not have full-time work, women who had experienced poor economic conditions in childhood, those living without a partner, and those who did not consume alcohol or smoke (OR varied from 1.10 to 1.70). Women with a low body mass index had higher odds of SFH (OR 1.37) than those with a moderate body mass index. SFH was positively associated with poor self-perceived health (OR 2.56). The odds of SFH increased with the number of concurrent health complaints, with an OR for 5–6 comorbidities of 4.93.

Competing Interests: The authors have declared that no competing interests exist.

Conclusion

We found an association between SFH, poor health, and different socio demographic and lifestyle characteristics. Women with SFH had increased odds of reporting multiple health complaints.

Introduction

Food hypersensitivity is a collective term for all adverse reactions to food [1]. In the medical literature, food hypersensitivity is categorized into allergic and non-allergic food hypersensitivity; the latter group has also been referred to as food intolerance [1]. Persons who self-report food hypersensitivity may have various diagnoses of allergic- or non-allergic food hypersensitivity from conventional practitioners, or they may have self-diagnosed or alternative medicine-diagnosed food hypersensitivity.

The field of food hypersensitivity is one in which much debate is taking place, and it seems to be characterized by a lack of solid scientific knowledge. It is a common perception that the prevalence of self-reported food hypersensitivity (SFH) is increasing [2, 3], and even though some studies on subgroups of SFH support this perception, this apparent increase is not well documented [4, 5]. Furthermore, studies show a disparity between the prevalence of food hypersensitivity based on self-report and the prevalence based on medical tests [6, 7]. This may imply that food hypersensitivity is overreported, but may also be related to the food hypersensitivity tests, which can have weaknesses or be laborious [2]. Moreover, some perceive SFH as an excuse for dieting [8], while others feel that some persons are misled by alternative medicine to believe they are hypersensitive to some foods [3]. Still others accept individuals' perception of their symptoms as being food-induced and emphasize the need for further research on the biological causes of food hypersensitivity [9]. Some of the suggested biological causes include the introduction of new foods, excessive hygiene, changes in the consumption of fatty acids, and changes in the microbiota of the gut [2, 10].

In order to give adequate health care attention to this heterogeneous group it is important that we learn more about the prevalence and the characteristics of persons with SFH. Food hypersensitivity in adults is often a long-term condition, and such conditions require continuous self-care work. [11–13]. The capacity to manage this type of ongoing self-care work, such as implementing a restricted diet, will be influenced by the person's resources and by eventual comorbidities [11–13]. It is therefore useful to know more not only about the prevalence of SFH, but also the characteristics of persons with SFH, and whether SFH is associated with other lasting health complaints.

A systematic review of prevalence studies concluded that the prevalence of SFH varied both between studies and between countries, with prevalence estimates ranging from 3% to 35% for any food [6]. One of the studies included in this review presented prevalence estimates of 4.6% in Spain, 19.1% in Australia, and approximately 16% in Norway [14]. The more recent Euro Prevall study underpins this heterogeneity, with self-reported adverse reactions to food in women varying from 5–8% in Lithuania, Greece, Poland, and Spain, to 30% in Germany [15].

Studies addressing the characteristics of persons with SFH indicate a female predominance [16, 17]. They further suggest that young women with higher education more often report adverse reactions to food than older women with lower education [17]. Another study indicated that individuals with SFH are more often absent from work, but that only 2% of that study sample felt that their income had been affected due to food-attributed symptoms [18].

A study from a clinical setting reported that fewer persons with SFH than controls consumed alcohol, but persons with SFH had the same degree of smoking and physical activity as controls [19]. A study on food allergy, one of the subgroups of SFH, suggested that it is more often reported among city residents [20]. Studies on other subgroups of SFH, such as individuals with Crohn's disease and gluten sensitive persons, indicated that they have a lower body mass index (BMI) than controls [21–23]. Other studies on celiac disease and irritable bowel syndrome showed that these diseases led to an increased burden on the subject's partner [24, 25], which may contribute to a lower degree of couple relationships among people with SFH. Previous studies documented the association between socioeconomic conditions in childhood and different health outcomes in adulthood [26], and this association may apply to SFH as well.

Ambiguous results have been reported concerning the overall health status of persons with food hypersensitivity [27]. In Poland, people with SFH reported a poorer overall health status than controls, while the opposite was observed in Spain, and in the UK and the Netherlands no differences were found [27].

According to studies from clinical settings, persons with unexplained or perceived food hypersensitivity report multiple health complaints more often than controls, including fatigue, musculoskeletal pain (among others back pain), depression, and fibromyalgia [9, 28]. Increased risk of depression and fatigue may also be related to untreated celiac disease [29], and celiac disease is associated with immune mediated diseases including autoimmune thyroid diseases [30].

In the present study, our first aim was to investigate the prevalence of SFH using a large representative sample. Our second aim was to illuminate the characteristics associated with SFH. Based on former studies, we hypothesized that SFH would be associated with young age, living in urban areas, having high education level, having low employment status, poor economy in childhood, not living with a partner, low alcohol consumption, and low BMI. We did not expect to find an association between SFH and income, smoking, or physical activity. Our third aim was to test the hypotheses that SFH is associated with poor health and with reporting multiple health complaints.

The large representative sample available to us was the Norwegian Woman and Cancer study (NOWAC). This sample included women 41–76 years, and as a result of this, the study was delimited to women belonging to this age span.

Materials and Methods

Data source

The NOWAC study is a population-based prospective cohort study, which was initially established to explore oral contraceptive use and other risk factors for breast cancer. The study has also been used to explore other cancer- and diet-related hypotheses, and has been described in detail elsewhere [31]. The NOWAC sample is randomly selected from the Norwegian Central Person Register, which contains information about all residents in Norway. Between 1991 and 2007 approximately 172,000 women aged 30–70 years were included in the study (overall response rate 52.7%). All women have given written informed consent to participate, and the Regional Ethical Committee for Medical Research Ethics and the Norwegian Data Inspectorate have approved the NOWAC study.

Participants recruited in the 1990s received a follow-up questionnaire in 2002–2005, and data from these questionnaires were used in the present cross-sectional analysis. Altogether 81,065 follow-up questionnaires were mailed, of which 64,316 were returned. All analyses in the present study were based on group anonymous data.

The follow-up questionnaire included basic questions on the use of oral contraceptives, reproductive history, family history of breast cancer, smoking, alcohol consumption, anthropometry, physical activity, and socioeconomic factors [32], as well as questions about health, health complaints, diet, and SFH. The question about food hypersensitivity was initiated by the following formulation: “Do any of the following conditions influence your diet?” Among the possible responses was the alternative “have allergy/intolerance”. We categorized women who ticked “have allergy/intolerance” as having SFH, and all others as not having SFH.

Statistical analysis

Data were analyzed using STATA version 14. Age was included as a continuous variable, since there was a linear association between age and SFH. Other study variables were categorized as follows: SFH (yes/no), place of residence (central–not central (reference)), duration of education (≤ 9 (reference), 10–12, 13–16, ≥ 17 years), employment status (full-time work (reference), not full-time work), economic conditions in childhood (good (reference), poor), partner status (living with a partner (reference), not living with a partner), alcohol consumption (< 0.1 , 0.1–4.9 (reference), 5.0–9.9, ≥ 10 g/day), smoking status (never (reference), former, current), BMI (< 20 , 20–24.9 (reference), ≥ 25 kg/m²) and self-perceived health (good (reference), poor).

The place of residence variable is based on Statistics Norway’s classification of centrality. “Central” includes municipalities with a regional center and a population of at least 50000, as well as municipalities that are within 75 minutes (90 for Oslo) travel from this regional center. The smoking variable was constructed based on the following two questions: “Have you during your life smoked more than 100 cigarettes?” (yes/no), and “Do you smoke daily now?” (yes/no). The question concerning self-perceived health is initiated with “Do you perceive your health as:”, and the respondents can tick off for “very good”, “good”, “poor” or “very poor”. Six possible health complaints, which had comprehensive interaction, were merged into one variable with the following categories: no comorbidities, muscle pain (myalgia) only, fibromyalgia/fibrositis only, low back pain only, depression only, hypothyroidism only, chronic fatigue only, two concurrent comorbidities, three concurrent comorbidities, four concurrent comorbidities, and five–six concurrent comorbidities.

Prevalence is presented as percentages, with 95% confidence intervals (CI). Characteristics of women with and without SFH are presented as means or percentages, along with associated p-values based on the Mann-Whitney test or the Chi-square test. Logistic regression analysis was conducted to investigate the association between SFH and participant characteristics, and odds ratios (OR) and p values are presented. The dependent variable was SFH, and the independent variables were age, place of residence, duration of education, employment status, economic conditions in childhood, partner status, alcohol consumption, smoking status, BMI, and self-perceived health. Due to an observed interaction effect, a term for interaction between smoking and alcohol consumption was included in the model. Self-reported physical activity level (“today” on a scale from 1 to 10) and household income were initially included in the model, but were not associated with SFH, and thus were excluded from the analysis.

A second logistic regression analysis was performed to investigate the association between SFH and reporting other health complaints. The same variables mentioned above were included, but self-perceived health was replaced with the health complaints variable.

Some of the variables had missing values (see [S1 Appendix](#) for the distribution of missing values). The depression and hypothyroidism variables had a relatively high percentage of missing values, and were recoded the following way: respondents with negative or missing answers who answered the subsequent question about when the depression or hypothyroidism started were coded as having depression or hypothyroidism, while the rest were coded as not having

depression or hypothyroidism. After this recoding, multiple imputation was conducted, using the chained equations procedure in Stata, and 20 datasets were created. The multiple imputation procedure included all variables involved in the logistic regression analyses, plus variables perceived as predictive of missing values (number of children, physical activity level, and income). After the imputation procedure, means of observed and completed data were compared, showing small differences. Results from the logistic regression analyses based on complete-case data showed results that were similar to those from the logistic regression analyses based on imputed data (see tables B and C in [S2 Appendix](#) for logistic regression based on complete case data).

Results

The study sample included 64,316 women aged 41–76 years (mean age 57.1 years), and 6.8% (95% CI: 6.7–7.0) had SFH. The mean age for women with SFH was lower than for women without SFH ([Table 1](#)). Women living in or near urban centers had higher odds of SFH than women living in less central parts of the country ([Table 2](#)). Women with more than 9 years of education and those without full-time work had increased odds of SFH. Respondents who had experienced poor economic conditions in childhood had higher odds of SFH, and this association was independent of age. A larger percentage of women with SFH were not living with a partner, had never smoked, did not consume alcohol, or was former smokers and non-consumers of alcohol. Moreover, women with a low BMI (<20) had a higher risk of SFH than women with a moderate BMI (20–24.9 kg/m²), and the SFH group contained more women with poor self-perceived health ([Table 2](#)).

The analysis which included the health complaints variable showed increased odds of SFH among women with muscle pain (myalgia), fibromyalgia/fibrositis, back pain, depression, hypothyroidism, or chronic fatigue syndrome, and the odds of SFH increased gradually with increasing number of concurrent comorbidities ([Table 3](#)). A testing of the association between SFH and the number of health complaints indicated an OR of 1.42 for each additional health complaint ($p < 0.001$).

Discussion

Main findings

We found a prevalence of SFH of 6.8% among adult women in the NOWAC study. The odds of SFH decreased with age, and was increased among women who lived in or near urban centers, those who had more than 9 years of education, those without a full-time job, with poor economic conditions in childhood, those living without a partner, non-drinkers, never smokers, former smokers who did not consume alcohol, and women with low BMI. However, we did not observe a significant association between SFH and income or physical activity level. SFH was associated with poor self-perceived health, and with reporting multiple health complaints.

The prevalence of SFH in the present study was relatively moderate compared to other studies. One reason for this may be related to how the question on food hypersensitivity was formulated. Respondents who reported having food allergy/intolerance were defined as having SFH, and all others as not having SFH. Consequently, some participants who did not answer the question may have been misclassified as not having SFH.

The age of the women in our study sample is relatively high compared to other studies [[14](#), [15](#)], which may have contributed to the moderate prevalence we observed, since older persons tend to have lower odds of reporting food hypersensitivity [[17](#)]. Another explanation may be that the NOWAC study contains a large random sample of women and does not specifically

Table 1. Characteristics of women with and without self-reported hypersensitivity (SFH), the Norwegian Women and Cancer study (complete case data).

	With SFH (n = 4,405)	Without SFH (n = 59,911)	p*
Age (years, mean)	56.1	57.1	<0.001
Place of residence (%)			
Central	59.0	55.8	
Not central	41.0	44.2	<0.001
Duration of education (years, %)			
≤9	22.9	28.4	
10–12	34.1	34.2	
13–16	28.4	25.9	
≥17	14.6	11.5	<0.001
Employment status (%)			
Full-time work	37.9	42.3	
Not full-time work	62.1	57.7	<0.001
Economic conditions in childhood (%)			
Good	70.0	73.2	
Poor	30.1	26.8	<0.001
Partner status (%)			
Living with partner	75.1	78.8	
Not living with partner	24.9	21.2	<0.001
Alcohol consumption (g/day, %)			
<0.1	22.1	19.9	
0.1–4.9	54.3	55.2	
5.0–9.9	15.5	16.5	
≥10	8.1	8.4	<0.002
Smoking status (%)			
Never	41.1	39.1	
Former	36.3	36.5	
Current	22.6	24.4	<0.008
Body mass index (kg/m ² , %)			
<20	7.1	4.9	
20–24.9	46.3	47.8	
≥25	46.6	47.3	0.018
Self-perceived health (%)			
Good	82.0	92.3	
Poor	18.0	7.7	<0.001

* P-value: Mann-Whitney or Chi-square test.

doi:10.1371/journal.pone.0168653.t001

focus on food hypersensitivity, thus minimizing the risk of food hypersensitive persons being overrepresented.

A larger proportion of young women, women in or near urban centers, and women with a high education level had SFH, which is congruent with studies from France and Germany [17, 20]. One may speculate whether this is due to a greater awareness of, or focus on, food hypersensitivity in these groups.

The fact that women who did not consume alcohol had higher odds of SFH is also consistent with other studies [19]. One possible explanation is that some persons are hypersensitive to alcoholic beverages [33], and there may be a correlation between being hypersensitive to

Table 2. Odds ratios (OR) with p values of self-reported food hypersensitivity by participant characteristics, the Norwegian Women and Cancer study (imputed data).

	OR	p
Age (years)	0.97	<0.001
Place of residence		
Not central (ref.)	1.00	
Central	1.10	0.003
Duration of education (years)		
≤9 (ref.)	1.00	
10–12	1.28	<0.001
13–16	1.45	<0.001
≥17	1.69	<0.001
Employment status		
Full-time work (ref.)	1.00	
Not full-time work	1.30	<0.001
Economic conditions in childhood		
Good (ref.)	1.00	
Poor	1.20	<0.001
Partner status		
Living with partner (ref.)	1.00	
Not living with partner	1.26	<0.001
Smoking status among non-alcohol consumers		
Never (ref.)	1.00	
Former	1.35	<0.001
Current	0.87	0.152
Smoking status among alcohol consumers (≥0.1 g/day)		
Never (ref.)	1.00	
Former	0.86	<0.001
Current	0.79	<0.001
Body mass index (kg/m ²)		
<20	1.37	<0.001
20–24.9 (ref.)	1.00	
≥25	0.98	0.467
Self-perceived health		
Good (ref.)	1.00	
Poor	2.56	<0.001

doi:10.1371/journal.pone.0168653.t002

food and to alcoholic beverages. It is also documented that alcohol may enhance hypersensitive reactions to food [34].

The association we observed between not smoking and SFH is not in line with a small study on SFH [19], but it is in line with another study that reported low tobacco use among patients with celiac disease [21]. The fact that former smokers who were non-drinkers had increased odds of SFH may indicate a change to a healthier lifestyle. This may be related to a general increased focus on healthy lifestyle, or personal experiences of alcohol and smoking as being detrimental to health.

The present study showed a negative association between SFH and full-time work, which persisted after controlling for self-perceived health. This is in line with studies which indicated more absence from work among individuals with SFH [18], as well as studies concluding that

Table 3. Odds ratios (OR) with p values of self-reported food hypersensitivity by comorbidity* in the Norwegian Women and Cancer study (imputed data).

Comorbidities	OR**	p
No comorbidities (ref.)	1.00	
Muscle pain (myalgia) only	1.80	<0.001
Fibromyalgia/fibrositis only	1.72	0.001
Back pain only	1.24	0.002
Depression only	1.30	<0.001
Hypothyroidism only	1.61	<0.001
Chronic fatigue only	2.55	<0.001
2 concurrent comorbidities	1.16	<0.001
3 concurrent comorbidities	3.02	<0.001
4 concurrent comorbidities	4.12	<0.001
5–6 concurrent comorbidities	4.81	<0.001

* The six comorbidities considered were muscle pain (myalgia), fibromyalgia/fibrositis, back pain, depression, hypothyroidism and chronic fatigue.

**Adjusted for age, place of residence, duration of education, employment status, economic conditions in childhood, partner status, alcohol consumption, smoking status, and body mass index.

doi:10.1371/journal.pone.0168653.t003

persons with chronic illness have less labor participation than others, even after controlling for physical disabilities [35].

Women who had poor economic conditions in childhood had increased odds of SFH. This finding may be seen in relation to the relatively well documented association between socio-economic conditions in childhood and different health outcomes in adulthood [26]. It has been suggested that early socioeconomic environment may influence diet, cognitive and emotional development, or changes in gene expression that can influence adult health [26].

The present study also indicated an association between SFH and living without a partner, which may be related to the increased partner burden that has been identified in subgroups of SFH [24, 25]. More generally, studies have concluded that persons with health challenges are less likely to be married, and suggest that this can be related to strains on the relationship [36].

The association between SFH and low BMI is in line with other studies on persons who avoid gluten or have Crohn’s disease [21–23]. Previous studies have also suggested an increased risk of inadequate nutrition in subgroups of SFH [37, 38], and the nutritional state among persons with SFH seems to be worth further investigation.

The present study indicated an association between SFH, poor self-perceived health, and one or more concurrent comorbidities. These findings are consistent with the majority of other studies [9, 28, 29, 39, 40], and indicate that a significant subgroup of women with SFH have poor health and comorbidities.

Strengths and limitations

The major strength of this study is the large and representative study sample, which was randomly selected among all women residing in Norway. An examination of external validity revealed no notable sources of selection bias or differences between the source population and NOWAC study participants, except for a somewhat higher education level [32]. There is a limited amount of representative studies of this magnitude, and as far as we know, the present study is the first to examine SFH using a representative sample of this size.

One weakness of this study is that the NOWAC questionnaires were not originally designed to deal with our research question. Another weakness is that the sample did not include men or younger women, thus our results cannot be generalized to the general adult population. A sample including younger women would have shown if the linear association we observed between age and SFH also applies to women in general. A sample including both sexes would have made it possible to compare the prevalence of SFH by sex, and may have revealed whether the findings related to women also applied to men.

The data used in the present study is from questionnaires sent in 2002–2005, which may be considered a weakness, since changes in prevalence may have occurred since then. As previously mentioned, the possible increase in SFH prevalence is not well documented [4, 5] and requires further research. Another weakness is that the analysis did not include all health complaints that may be related to SFH, for example asthma, allergic rhinitis, and eczema, which are conditions that often accompany food allergies [41].

Other weaknesses of the present study are related to the missing values. Missing values on the depression and hypothyroidism variables were recoded to 'no', based on the assumption of a connection between not responding and not having these conditions. Although this may have led to misclassification, we believe that recoding is preferable to other approaches. For other missing values, multiple imputation was conducted in order to preserve information from subjects with missing values [42]. Multiple imputation relies on the assumption that values are missing at random [42], but one can never conclude this with certainty. For example, some respondents may omit an answer because they find the categories inappropriate, and these people may tend to belong to particular groups.

Conclusions

The present study indicates a relatively low prevalence of SFH in Norwegian women, and should be taken into account when debating the extent of SFH. The study also showed an association between SFH, poor health and reporting several health complaints. This indicates that a subgroup of women with SFH may need relatively complex health care interventions. In addition, poor health and having to manage additional health complaints may influence one's capacity to implement a restricted and sometimes challenging diet, and a poorly implemented diet may affect health. Food hypersensitivity, be it SFH or more specific food hypersensitivity, is a topic on which more research is required.

Supporting Information

S1 Appendix. Missing values.

(DOCX)

S2 Appendix. Logistic regression based on complete case data.

(DOCX)

Acknowledgments

The authors would like to thank the NOWAC study participants for their vital contribution.

Author Contributions

Conceptualization: MJ BA TB AO.

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Formal analysis: MJ TB.

Methodology: MJ BA TB AO.

Project administration: MJ.

Resources: TB.

Supervision: BA TB AO.

Validation: MJ BA TB AO.

Visualization: MJ.

Writing – original draft: MJ.

Writing – review & editing: MJ BA TB AO.

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The work of managing food hypersensitivity: A qualitative study

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Keywords: Food hypersensitivity; self-management work; Normalization Process Theory; diagnosis; stigma.

Abstract:

In recent years, there has been an increasing focus on the self-management work that comes with having a long-term condition. However, the self-management work involved in food hypersensitivity (FH) has not been explored. In this study, we explored the self-management work of adult women with FH. We conducted 16 semi-structured, qualitative interviews with women with FH aged 39-67 years. The normalization process theory informed the interview guide, and a template analysis was conducted. Our study showed that the self-management work related to FH may represent a comprehensive workload, and some participants also worked to conceal their FH. Participants who learned which foods caused symptoms were able to concentrate on the work of implementing a restricted diet, which could eventually become routine. However, participants who did not determine which foods caused symptoms had to continue the work of understanding their FH, implementing restricted diets, communicating their diet to others, and evaluating their management plan.

1. Introduction

The number of persons living with one or more long-term conditions continues to increase, which is why such conditions are now considered to be one of the largest challenges faced by healthcare services (Norwegian ministry of health and care services, 2015). Long-term conditions cause symptoms and functional limitations, which imply a burden on the individual and their family; this burden is referred to as ‘the burden of illness’ (Boehmer, Shippee, Beebe, & Montori, 2016; Kahn et al., 2015). In addition, the management of chronic conditions requires continuous work which, among other things, entails carrying out personal self-management regimens and engaging with healthcare providers (Gallacher, May, Montori, & Mair, 2011). This self-management work and the impact the workload has on functioning and well-being is referred to as ‘the burden of treatment’ (Eton et al., 2012).

In recent years, there has been an increasing focus on the continuous self-management work that comes with having a long-term condition, and the reality that this workload can become overwhelming if it exceeds one’s capacity to address it (May et al., 2014). This in turn can lead to non-compliance, poor health outcomes, and wasted healthcare resources (May et al., 2014; May, Montori, & Mair, 2009). Thus, researchers argue that it is important for healthcare providers to pay attention to self-management work and endeavor to keep the workload manageable for the patient (Eton et al., 2012; Kahn et al., 2015; Leppin, Montori, & Gionfriddo, 2015; Sav et al., 2013).

Previous studies have focused on measuring the burden of treatment and have tried to describe the nature of this burden for different long-term conditions (Eton et al., 2017; Gallacher et al., 2011; Kahn et al., 2015). Among other things, studies have described the nature of self-management work among persons with heart disease, stroke, chronic kidney disease, and multiple long-term conditions (Gallacher et al., 2011; Gallacher, May, Langhorne, & Mair,

2018; Kahn et al., 2015; Sav et al., 2013). However, the self-management work of food hypersensitivity (FH) has not been described.

FH is a collective term for all non-toxic, adverse reactions to foods (Johansson et al., 2001) and is relatively common (Jakobsen, Braaten, Obstfelder, & Abelsen, 2016; Rona et al., 2007). The self-management work of FH consists of detecting which foods give symptoms and avoiding or reducing the ingestion of these foods (Bolle, 2012), i.e., carrying out a restricted diet. Studies have indicated that the preparation of a special diet takes time and may imply a discernable burden of treatment (Shah et al., 2014; Yen, McRae, Jowsey, & Bagheri, 2013). Furthermore, studies have indicated an association between FH and other long-term conditions (Dominguez-Ortega et al., 2014; Jakobsen et al., 2016; Lind et al., 2005; Zingone et al., 2015). This means that a subgroup of people with FH also suffer from other long-term conditions that require self-management work. Studies have shown that the presence of more than one long-term condition increases the risk for a patient to become overwhelmed by their total self-management workload, and thus some self-management work may not be carried out (May et al., 2014; Sav et al., 2013).

In this article, FH includes conventional medicine-diagnosed (CMD) FH, self-diagnosed FH, and alternative medicine-diagnosed FH, so as to encompass all persons who carry out FH management work. Further, CMD FH includes both test-based CMD FH (such as celiac disease, lactose intolerance or food allergies) and CMD FH based on symptoms and exclusion of other diseases (such as irritable bowel syndrome) (Bolle, 2012; Woolthuis, Brummer, de Wit, Muris, & Stockbrugger, 2004). However, previous studies have indicated that patients with test-based CMD FH, such as food allergies, are met with more understanding from healthcare workers, friends, and family than those who with self-diagnosed FH or alternative medicine-diagnosed FH (Nettleton, Woods, Burrows, & Kerr, 2009, 2010). Therefore, we assumed in this paper that persons with test-based CMD FH would benefit from more understanding when carrying out

their self-management work compared to those who lack such a diagnosis, and that this understanding would make their self-management work easier.

Another aspect that may influence the self-management work of FH is the fact that persons who follow a restricted diet can experience stigma, as has been reported in earlier studies, and therefore some conceal or even compromise their restricted diet to avoid this (Diesen, Wiig, Grut, & Kase, 2015; Olsson, Lyon, Hörnell, Ivarsson, & Sydner, 2009). Stigma is thoroughly described by Erving Goffman, who defined it as ‘the situation of the individual who is disqualified from full social acceptance’ (Goffman, 1968:9). Goffman distinguishes between ‘discredited’ persons, who cannot conceal the attribute that leads to stigma, and ‘discreditable’ persons, who can conceal the stigmatizing attribute and thus avoid stigma (Goffman, 1968). Studies indicate that persons with a restricted diet belong to the latter group, since the attribute that leads to stigma is visible only when food is served (Diesen et al., 2015; Olsson et al., 2009). Furthermore, the act of concealing is described as work that is continually performed by ‘discreditable’ persons when they interact with new people (Malterud & Bjorkman, 2016).

As in previous studies (Gallacher et al., 2011; Kahn et al., 2015), we used the Normalization Process Theory (NPT) to identify, describe, and categorize the different aspects of the self-management work. The NPT encompasses four core constructs that can elucidate the self-management work of long-term conditions (Gallacher et al., 2011; Kahn et al., 2015): coherence, collective action, cognitive participation, and reflexive monitoring. Coherence, or ‘sense-making work’, refers to the effort of learning about the long-term condition, its consequences, and its treatment. Collective action, or ‘enacting work’, means implementing or carrying out the self-management work, and adapting daily activities to the long-term condition. Cognitive participation, or ‘relationship work’, includes engagement with others to manage the condition, as well as mobilizing support from others. Finally, reflexive monitoring, or ‘appraisal work’, means altering and appraising treatment regimens. This includes evaluating whether the

treatment plan has to be amended, deciding what amendments to make (Gallacher et al., 2011; Kahn et al., 2015).

Because FH is relatively common, require self-management work, and since this self-management work may influence one's capacity to carry out other self-management work, we find it important to explore the self-management work of FH. Therefore, in this study, we aim to explore the nature of self-management work of FH, and to investigate how having test-based CMD FH influences this work. We used NPT to identify, describe, categorize, and discuss the different aspects of self-management work for FH. This study is a product of a project that includes only adult women; thus, the present study is restricted to this group.

2. Methods

2.1. Design and sample

In order to explore the self-management work of FH, we conducted semi-structured, qualitative interviews of 16 women with FH aged 39-67 years (mean age 49.7 years). To illuminate how test-based CMD FH influences the self-management work of FH, we included eight women with and eight women without this kind of diagnosis (Table 1).

All participants had children, and nine had minor children. Fourteen of the participants were living with a male partner, and two were living without a partner. Six participants had a master's degree, six had a bachelor's degree, and four had secondary school as their highest completed education level. Eight participants described having other CMD long-term conditions, such as diabetes, rheumatoid arthritis, fibromyalgia, asthma, or allergies that required daily medication. Most of the participants said they were hypersensitive to more than one food, and during the interviews, some of those with test-based CMD FH expressed that they also had other FH

conditions, such as irritable bowel syndrome or self-diagnosed FH. In general, the women described having FH or symptoms of FH that had lasted for years or decades.

Table 1 Participant characteristics

	Test-based conventional medicine diagnosed food hypersensitivity	Age (years)
Dina	Yes, celiac disease	39-49
Eline	Yes, celiac disease	50-59
Grethe	Yes, celiac disease	50-59
Carina	Yes, celiac disease and lactose intolerance	60-67
Anna	Yes, lactose intolerance	39-49
Helen	Yes, food allergies	39-49
Mary	Yes, food allergies	39-49
Ruth	Yes, food allergies	50-59
Frida	No	50-59
Lena	No	39-49
Irene	No	39-49
Kristina	No	60-67

Sarah	No	39-49
Jeanette	No	50-59
Nina	No	50-59
Brita	No	50-59

Most participants were recruited through The Norwegian Asthma and Allergy Association and Norwegian Celiac Association, or through acquaintances of the first author. In addition, one woman self-recruited when she heard about the project topic. The interviews took place in five different towns in Norway, lasted 53-98 minutes (mean 67 minutes), and were carried out from August until November 2016.

Before the project started, a remit assessment was sent to the Regional Committee for medical and health research ethics (REC) North. REC North responded that this project did not require approval from them (2014/1565). After this, the Norwegian Centre for Research Data (Project number 40138) was notified of the project, which is normal procedure in cases where ethical approval for collecting personal data is not needed. All women gave written consent before they participated in the study.

2.2.Data collection and analysis

The first author conducted the interviews and analyzed the data in close collaboration with the other authors. The interview guide was inspired by the NPT and Gallacher et al.'s operationalization of the NPT (Gallacher et al., 2011:237). As mentioned, according to the NPT, the self-management work of a long-term condition encompasses four core constructs: coherence (understanding the illness and treatment), collective action (enacting work), cognitive participation (engaging with others to manage the condition), and reflexive

monitoring (evaluation work) (Gallacher et al., 2011; May, 2010; May & Finch, 2009). Thus, the central topics in our interviews were: what had the participants done to understand their FH and how it can be managed; how did they carry out the practical work of managing their FH (for example grocery shopping and food preparation); how did they handle eating with others and how did they instruct others about their condition and chosen management; and how did they evaluate and alter their management and routines.

The interviews were initiated by asking the participant to explain how she found out that there are food(s) she cannot tolerate. Most participants gave thorough answers to this question, and the answers contained information about the coherence-, cognitive participation-, collective action- and/or reflexive monitoring work of managing FH. The interviewer used this information to pose follow-up questions about the work of managing FH. This procedure was used for most of the interview. However, at the end of the interview, the interviewer looked through the interview guide to make sure all topics were covered, and asked questions about any remaining topics. All interviews were audio recorded and transcribed by a professional transcriber, and the transcriptions were read through to become familiar with the data.

The analysis was inspired by template analysis, as described by King (2004) and Brooks et al. (2015). The analysis was started by making a coding template, that is, a list of codes, in which each code represented a specific type of self-management work. Four of these codes were inspired by NPT and defined *a priori*: (1) coherence work, (2) collective action work (3), cognitive participation work, and (4) reflexive monitoring work. As the interviews showed that some participants conducted self-management work to conceal their FH, (5) concealment work, was added to the coding template.

After the coding template was made, the first author read through each interview, noted all descriptions of self-management work of FH, and categorized the work as per the coding template. Then these notes were thoroughly read through to identify patterns and differences,

as well as relationships between different types of self-management work. The interviews showed that the coherence work consisted of several elements and was a crucial part of self-management work, and therefore this work is presented in both chapters 3.1 and 3.2. Conversely, the interviews contained little information about reflexive monitoring work, and therefore a description of this work is included in the chapter on collective action work (chapter 3.3). Cognitive participation and concealment work are presented in chapters 3.4 and 3.5, respectively.

3. Results

The interviews showed that the self-management work of FH can be comprehensive, and the women conducted the vast majority of this work by themselves, with little help from healthcare services or their social network.

3.1. Coherence: Identifying which foods cause symptoms

The women's descriptions led to the identification of four main types of coherence work. The first included women who, after a long period of poor health, usually with further deterioration, contacted a general practitioner. This contact led to a clinical examination and a positive FH test. Participants described this positive test as a "breakthrough", followed by an immediate change in diet and significantly improved health. One participant diagnosed with celiac disease diagnosis said:

When I had [the name of her son], I breastfed him for 1 year and then went back to work; my reserves were probably empty, so I got very sick. I lost 25 kilos and was sick all the time. I caught almost all the germs that were going around, and I finally went to my general practitioner and said, "You have to find out what is wrong with me".

The participant asked her general practitioner to test her for celiac disease, and the test turned out to be positive. She was grateful for the diagnosis because then she knew what foods did not tolerate:

I think about this a lot (...) there are people who feel that there is something they do not tolerate and are sick all the time and try lots of diets and lots of treatments, but they do not get well. So, I think that I am very lucky to have received a diagnosis.

The second type of coherence work was related to participants who avoided an increasing number of foods. These participants described a long-lasting initial phase, during which they experienced symptoms, but did not understand what caused them. Gradually, they realized that a food was causing the symptoms, and after removing this food from their diet, the participants experienced a 'peaceful' period until a new food gave similar symptoms (usually strong acute symptoms), and the participant concluded that they were hypersensitive to this food as well. One interviewee reported that from time to time she became hypersensitive to new foods:

Chili was not included in many products here in Norway, so I had really a peaceful period. (...) But later new problems arose, and I discovered that I also could not eat chili. It is almost as if you go up a mountain, overcome an obstacle, and then there are plains where you can relax a little. Then you have to climb a new slope to the next peak.

The third type of coherence work may also be perceived as iterative, but the women avoided a decreasing number of foods. These women had experienced a long period of severe gastrointestinal symptoms. When they contacted health services, they found that health services could not offer any help. Therefore, they contacted alternative clinics, who advised them to start a very restricted diet, or they started a very restricted diet on their own. Later on, they gradually reintroduced foods. The reintroduction was initiated by the women themselves, following a low

FODMAP¹ diet, or was carried out after advice from an alternative medicine provider. One interviewee described the reintroduction process:

I was supposed to test it out; eat a tablespoon or so of a potato. So I would do that for 3 days and let it rest. Then I would do the same thing with a new food. It was a kind of rotation diet, and it was a cautious approach to it. I continued this for a long time.

The fourth type refers to an often long and comprehensive process of finding out to which foods one is hypersensitive, without succeeding. One interviewee described contacting healthcare services, taking a celiac disease test, a lactose intolerance test, and allergy tests, contacting an alternative clinic, reading books, searching the internet, and eliminating and reintroducing foods:

You search high and low when you are as afflicted as I have been. You have to search, because [the condition] influences the quality of your life very much.

As indicated above, many of the women with test-based CMD FH described experiences in accordance with the first type of coherence work. Correspondingly, most of the women without such a diagnosis described experiences that were in line with the other types.

Some participants had both symptoms of unclarified FH and symptoms of other unclarified conditions. These participants felt they could only discuss one of these conditions with their general practitioner, and this delayed the process of identifying which foods cause symptoms.

A study participant explained:

It gets difficult to decide what to put forth when you go to the general practitioner. You have to (...) prioritize what you should focus on.

¹ FODMAP - Fermentable Oligo-, Di- and Monosaccharides and Polyols (Gibson & Shepherd, 2010)

3.2.Coherence: Understanding what concrete products to eat

In general, the women described having to exert effort to understand the severity of their FH, to find out which products and dishes to eat, and to adjust their eating habits. This work was more challenging and comprehensive if the women were hypersensitive to many foods and foods that were present in common products and meals. Indeed, some participants described the work as so demanding that they tended to eat only a few, familiar, ‘safe’ dishes.

We did, however, observe a difference between participants with CMD celiac disease and others. Women with celiac disease said they received information from healthcare services about the severity of the condition and what concrete products and meals to eat. The participants described this information as very useful, and as something that effectively contributed to their understanding of the condition and how to manage it.

On the other hand, participants without celiac disease described a process in which they had to find all the information about their condition themselves, which could take a long time. One study participant with CMD lactose intolerance verbalized this:

In the beginning, it was a lot of finding out what I could use instead. (...) I found out that here in Norway there is milk in everything (...) in stuff you could not dream that there would be milk in. (...) With regard to my health, I suppose it took me a long time to realize or conclude that it was indeed important for me not to consume milk products at all; that this was of great importance to my health.

Participants who had not found out which foods caused symptoms, the severity of the condition, or which products and meals they could eat, continued to conduct coherence work, while participants who had clarified these issues could complete the coherence work of understanding their condition. They could focus on other kinds of self-management work, such as the practical work of shopping and preparing food, which is described in the following chapters.

3.3. Collective action: Carrying out a restricted diet

In general, the women described that they spent more time shopping for groceries and preparing food now than they did before they implemented a restricted diet. They read ingredient labels consistently and made more food from scratch. Some used health food stores or bought foods abroad, since the selection was larger. Some discussed recipes with others, searched the internet for recipes, and/or used weekends or evenings to prepare food for the next days. One study participant reported spending 1 hour each evening to make herself food for the next day:

You have to find time [to make food]. (...) I make [food for the next day] once the children have gone to bed. (...) It takes me approximately 1 hour. (...) I have to; I do it because it keeps me healthy, and I do not want to go back to where I was. I want to work, I want to stay healthy.

According to the participants, they had a persistent awareness of and made a continuous effort to avoid foods that caused symptoms when they prepared food for themselves. This degree of awareness seemed to be influenced by the severity of symptoms, and both participants with and without test-based CMD FH described long-lasting, severe symptoms.

As indicated, participants reported that grocery shopping and preparing special food demanded self-management work. However, some participants also had one or more additional long-term conditions that required separate self-management work. These participants did not describe their total self-management workload as too large or overwhelming. However, they did say that, while their other, non-FH-related long-term conditions were addressed by health services, their FH was often overlooked, which again increased participants' awareness of the FH. A participant reported:

I always tell [doctors and hospitals] that I am lactose intolerant. But I have still been given tablets that are full of lactose. (...) I did not understand why I was so sick when I used these medications. (...) Today I am aware of it, and when I receive medicine from doctors or the hospital I ask.

Some women, who knew to which foods they were hypersensitive, mentioned that after months or years with the same food restrictions, shopping and preparing food had become routine. To a small extent, these women evaluated their management plan, and their ‘reflexive monitoring’ (evaluation) work was limited to paying attention to new products and recipes. Participants who had not been able to determine which foods caused symptoms did, on the other hand, continuously evaluate and change their diet, which led to a low degree of routine.

3.4. Cognitive participation: Eating with others

The women presented different strategies related to eating at friends’ homes, restaurants, cafes, etc. Some of these strategies included letting the hosts know in advance about their FH, clarifying the contents of food with the chef, asking their husbands to taste food first, bringing their own food, reading ingredient labels on foods other people had bought, picking out the foods they could tolerate, and observing other people’s food preparation, which they had learned was necessary.

The previously described awareness women used when preparing their own food seemed more apparent when they ate food that others had prepared. One participant compared her work of avoiding foods that caused symptoms to a “hard disk that was continuously processing data”:

Compared to the many who do not have these issues, I believe that I have a hard disk that runs in the background and processes data continuously. (...) at a meal that I do not control 100%, I must somehow scan and think through. If I sometimes choose to eat something that I am unsure of (...) there may be consequences, I may have strong pains.

(...) It takes a lot of effort, it buzzes around in the back of your mind, managing it, juggling it, keeping your body well and avoiding pain.

Some women also described significant awareness at home. One participant with celiac disease explained how she washes her kitchen before she starts making her own food:

Yes, because at home it is worse, because they forget. (...) I have to wash everything.

(...) In fact, my risk is highest at home.

Irrespective of whether they had test-based CMD FH or not, participants described that their FH was met with varying reactions from others. While some met their FH with understanding, others did not. A participant with CMD food allergies gave an example of the latter:

Their opinion seemed to be (...) ‘if you are not going to die from it, you can happily eat it’.

3.5. The work of concealing

Independent of diagnosis, participants had different degrees of openness related to their FH. One study participant gave an example of selective openness:

I am not a person that makes a fuss about it. I do not talk about it or ask for adaptations.

(...) Yes, it [another long-term condition] is a part of me that I cannot hide. (...) I can hide the FH a bit more.

The participants who hid their FH described different strategies of concealment, and thus different concealment work. Some brought their own food and tried to find a way to eat it without being noticed. Others searched for something ‘safe’ to eat without revealing that they had restrictions, and some ingested foods that gave them symptoms to avoid revealing their hypersensitivity.

Some of the reasons women mentioned for being selectively open about their FH included not wanting to be the center of attention, the desire not to bother others, feeling that not being able to eat everything would be associated with weakness or mental disease, and not wanting to be associated with modern diets or with women who are obsessed with food. One interviewee said:

When I was an allergic in the 1980s (...) it was something rare. (...) There was not the same focus on food that there is today (...). But now, like with gluten, I think even people without celiac disease avoid gluten because they have read that gluten is unhealthy. And there are people who avoid lactose who have no proven [hypersensitivity] or experience of strong discomfort or pain. (...) I do not want to be associated with those who have an almost unhealthy obsession with food.

4. Discussion

FH can entail a significant self-management workload, in particular for those who avoid many foods and foods that are ingredients in common products and meals. The women participating in this study conducted the majority of the work themselves. We observed four types of coherence work women did to identify foods that caused symptoms: through a breakthrough, as an iterative increasing process, as an iterative decreasing process, or as remaining unclarified. The first type of coherence work implied a clarification of which foods caused symptoms, and therefore an opportunity to concentrate on the work of implementing a restricted diet, which could eventually become routine. The last three types, however, implied iterative coherence work in order to make sense of the FH, which further contributed to the iterative work of implementing dietary restrictions, instructing others, and conducting appraisals. Women with FH diagnoses based on medical tests represented the first type, as the

medical tests clarified which foods to avoid. Interviewees described that the process of diagnosing other health complaints delayed the process of diagnosing the FH.

Women with celiac disease received information from health services about the severity of their condition and what products to eat. This information, like diagnostic help, enhanced women's understanding of the condition and its treatment, which provided the opportunity to move on to the practical work of carrying out a restricted diet.

The women described a continuous awareness of foods that triggered symptoms and a sustained effort to avoid them, and this attention increased when they were eating with others and when their FH was overlooked or forgotten by others. In addition, some women also worked to conceal their FH. Some of the reasons they gave for doing this were not wanting to be the center of attention, not wanting to bother others with their restrictions, not wanting to be associated with weakness, and not wanting to be associated with modern diets. Our presumption that those with test-based CMD FH would be met with more understanding was not confirmed by the study.

As mentioned, FH may result in a comprehensive self-management workload. This finding is in accordance with a study on the management of celiac disease (Shah et al., 2014), as well as studies on other long-term conditions (Gallacher et al., 2011; Sav et al., 2013). Some of the self-management workload of FH can be explained by the fact that we eat several times each day, and in different settings.

While other studies have emphasized that the burden of self-management work is placed on both the patient and his or her network (May et al., 2014), the participants of the present study received little help from others and conducted the vast majority of self-management work themselves. One possible reason for this may be related to the fact that health services for adults with FH have been characterized by lack of competence and sparse resources (Bolle, 2012; Lindstad, 2012); thus health care services may have offered little support to adults with FH.

Furthermore, studies have indicated that women, to a larger degree than men, are responsible for household meals and the health of the family (Andersen, 2008; Bugge, 2006), and one cannot rule out that these gender-related factors contributed to the experience of our participants.

The present study shows that the self-management workload of FH may be comprehensive. Other studies have indicated that FH is associated with other long-term conditions (Dominguez-Ortega et al., 2014; Jakobsen et al., 2016; Lind et al., 2005; Zingone et al., 2015), and some studies concluded that the management of several long term-conditions may lead to a large self-management workload, which in turn may lead to low compliance, poor health outcomes, and wasted health resources (May et al., 2014; Sav et al., 2013). On this basis, one may speculate that some persons with FH use a large amount of their capacity on the self-management work of FH, which may reduce their capacity to manage other long-term conditions, which again may have consequences for their health. Therefore, it may be advantageous to reduce the self-management workload of FH. According to the present study, this can be done through reducing the ‘coherence’ work of finding out which foods cause symptoms, as well as what concrete products to eat, since such clarification makes it possible to move on to the practical work of implementing a restricted diet, which can later become routine. A clarification of what foods cause symptoms also has the potential to lead to better health and fewer unnecessary food restrictions (Strinnholm, 2017). However, this would require greater attention, increased resources, improved education of healthcare providers, and enhanced medical research on FH.

Participants with symptoms of both an unclarified FH and other unclarified conditions, described that they had to choose which one of these conditions to discuss with their general practitioner, which delayed the process of diagnosing FH. This may be an example of the well-documented fact that health services are better suited to manage single health conditions than

multiple health conditions, even though a considerable number of patients have multiple health conditions (Norwegian ministry of health and care services, 2015).

According to Jutel, a diagnosis provides an acceptable explanation for deviance from the norm (Jutel, 2009; Jutel, 2011), and thus one may assume that persons with a test-based CMD diagnosis would be met with more understanding when following a restricted diet than those who did not have such a diagnosis. However, the present study did not support this assumption, since the participants had varying experiences irrespective of diagnoses. One explanation for this may be that some women in our sample with test-based CMD FH also had FH that was not diagnosed through medical tests, and thus these participants had experiences related to both.

One possible explanation as to why some participants were met with understanding regardless of diagnosis, may be related to the increasing expectation in the last decades that people should actively take care of their health, including through regulating food intake (Beck & Beck-Gernsheim, 2001; Mielby, 2015). Thus, our participants' active investment in avoiding foods that cause symptoms is largely in line with this expectation. Furthermore, it may be that the imperative of attending to one's own health in some contexts carries more weight than the demand for a medical diagnosis.

Our participants both with and without test-based CMD FH experienced negative reactions towards their restricted diet, which may be explained by the strong social rules related to the meal (Diesen et al., 2015; Quandt, 2006). One of these rules is that adult persons should eat all foods they are served, or at least a large variety of foods (Fischler, 1988; Nettleton et al., 2010), and a restricted diet implies breaking this rule.

The present study showed that participants concealed their restricted diets, and some ate foods they did not tolerate in order to conceal their FH. This behavior has been described in former studies, which suggested stigma as one of many possible explanations for low adherence to recommended treatment (Diesen et al., 2015; Olsson et al., 2009).

The concealment of a restricted diet can be seen in light of Goffman's writing about stigma (Goffman, 1968). Goffman wrote that 'discreditable' persons conceal the stigmatizing attribute in order to avoid stigma (Goffman, 1968). Malterud et al. further described such concealment as a piece of work continually performed by the 'discreditable' person as he/she interacts with new people and in new contexts (Malterud & Bjorkman, 2016). It is also emphasized that 'discreditable' persons not only conceal, but also make decisions about whether they want to conceal or reveal the cause of stigma (Clair, Beatty, & Maclean, 2005), and they make decisions about and carry out concrete strategies when revealing or concealing (Clair et al., 2005). In other words, 'discreditable' persons, including persons with FH, not only conduct the work of concealing, but also the work of deciding to reveal or conceal and the work of revealing.

This work of concealing and revealing requires some degree of effort; some of the patient's capacity may be used to conduct concealing and revealing work, which may reduce their capacity to do other tasks. If this is the case for persons with FH, it likely also applies to patients with other long-term conditions.

There are some limitations of this study. One is that the study only includes women aged 39-67 years, as inclusion of men and younger women might have given somewhat different findings. For example, previous studies concluded that women are more often responsible for household meals than men (Bugge, 2006). Thus, one cannot rule out that a study of men might show a smaller self-management workload of FH, since women do a considerable amount of food-related work.

The fact that only the first author analyzed the data can also be seen as a limitation, since two researchers may see more nuances in the data than one (Malterud, 2011). Further, the *a priori* themes and template, which is a particular feature of template analysis (Brooks et al., 2015; King, 2004), may have led to less openness to other topics in the interviews (King, 2004). However, as pointed out by King, the structure of template analysis works well when one wants

to compare the experiences of different groups (King, 2004). On the other hand, our comparison of participants with and without test-based CMD FH may have been influenced by the fact that some participants with such a diagnosis also had other, undiagnosed FH. However, this does draw attention to the fact that some persons have complex FH conditions, which require relatively complex diagnostic efforts and may imply a considerable burden of treatment.

5. Conclusions

The present study showed that the self-management workload of FH can be significant, and the women participating in this study conducted the majority of this work themselves. We identified four types of coherence work related to identifying which foods caused symptoms: through a breakthrough, as an iterative increasing process, as an iterative decreasing process, or as remaining unclarified. The first type implied a clarification of which foods caused symptoms, and therefore an opportunity to concentrate on the work of implementing a restricted diet, which could eventually become routine. The last three types, however, implied iterative coherence work of identifying which foods cause symptoms and understanding what concrete products to eat. This further contributed to iterative work of implementing diet restrictions, instructing others, and evaluating the diet. Some women also worked to conceal their FH, because of the stigma of revealing their restricted diet. Our presumption that those with test-based CMD FH would be met with more understanding was not confirmed by the study.

Healthcare providers need to consider the work entailed in managing FH. Help in clarifying which foods cause symptoms and what concrete products to eat may reduce this work, and thus increase the capacity for patients to perform other tasks. However, this requires a greater focus on FH, as well as increased expertise and resources.

Declaration of Conflicting Interests: The authors declare that there is no conflict of interest.

Funding: The first author was supported by the Department of Community Medicine, UiT The Arctic University of Norway [grant number 4025]. The funders had no role in study design, data collection, analysis, interpretation or writing of the manuscript.

Acknowledgments: The authors would like to thank the interviewees and those who have helped us recruit interviewees for their invaluable contribution.

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RESEARCH ARTICLE

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What makes women with food hypersensitivity do self-management work?



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Abstract

Background: Managing a chronic condition takes work, and it is considered important that patients carry out this work. However, knowledge is lacking on what elements enhance self-management work.

Persons with food hypersensitivity (FH) seem to do self-management work despite the relatively little support they receive. Our aim is to explore what makes women with FH carry out the work of managing their condition. Our research will shed light on the health care needs of women with FH and contribute to the knowledge on self-management among persons with chronic conditions.

Methods: We used the Self-determination theory and the Conservation of resources theory to analyze 16 qualitative individual interviews with women with FH aged 39–67 years.

Results: Our participants reported that eating selected foods resulted in uncomfortable symptoms, and their main motivation for carrying out self-management work was the wish to avoid these symptoms and their consequences. Participants' individual resources were crucial to the management of FH, and those who had a social network that included people with relevant competencies clearly benefited from this.

Hindrances to the management of FH included competing priorities and not wanting to break with the social expectation of sharing a meal.

Conclusions: Women with FH carried out self-management work because they were highly motivated. Important motivators included the uncomfortable symptoms that resulted from consuming some foods, which had negative consequences on their lives or could bring shame. The ability to perform self-management work was dependent on the availability of individual and social resources. Indeed, women with FH who have the individual and social resources necessary to manage their condition may not need health services, whereas those who do not have these resources, or have significant competing priorities, may need assistance from health services.

The desire to avoid uncomfortable symptoms can be a motivator for persons with chronic conditions to do self-management work, while a lack of symptoms can reduce motivation. The competing role of basic needs can take two forms: when fulfilled, these needs may contribute to self-management work; however, people may opt out of self-management in order to fulfil basic needs.

Keywords: Food hypersensitivity, Chronic conditions, Motivation, Resources, Conservation of resources (COR) theory, Self-determination theory

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Background

The number of persons with chronic conditions is increasing [1, 2]. This presents a challenging and costly problem for health services, which tend to assign more and more of the work of managing such conditions to the patient [3]. It is considered important that patients do this work, both because it is important for their health and because it lessens the burden on the health care system [4–6]. However, patients do not always conduct this work, which is seen as a major problem and a growing concern [5]. Studies have tried to illuminate what may increase self-management work among patients, but knowledge is still lacking [5].

However, studies do argue that the degree to which self-management work is done depends on the patient's degree of motivation [6]. According to the Self-determination theory (SDT), high-quality motivation requires patients to internalize values and skills for change [7], and high-quality motivation is more likely to be achieved if three basic psychological needs are satisfied: the need to be 1) competent, 2) autonomous, and 3) related to others [7, 8]. The quality of motivation is also influenced by the goals that are set. For example, intrinsic goals like personal growth and health may result in higher-quality motivation than extrinsic goals such as wealth [7].

While SDT addresses the elements that contribute to high-quality motivation, the Conservation of resources (COR) theory addresses the actual motivators, and discusses how resources and external conditions influence our ability to do what we are motivated to do. The basic tenet in COR theory is that people use available resources to retain, foster, and protect the things they value [9, 10], such as peace, family, self-preservation, well-being, a positive sense of self, and health [9:228]. To protect these things, we use different resources, including material, personal (e.g. skills), and social resources [9]. These resources are strongly associated. For example, individual resources like self-esteem, self-efficacy, and optimism are correlated with social support. Thus, individual resources and social support run in 'packs', referred to as 'resource caravans' [9]. According to COR theory, the loss or gain of resources can trigger negative or positive resource cycles: people who lack or lose resources are more vulnerable to further resource loss, and achievement of new resources can start positive processes that lead to further resource achievement [11].

According to COR theory, conditions that are external to the individual can also influence people's ability to protect the things they value; these external conditions are called 'resource caravan passageways' [9]. Supportive resource caravan passageways enhance people's resource reservoirs, and thus their ability to protect what they value. Physical safety, clean water, and good schools are examples of caravan passageways that support people's

resource reservoirs [9]. Supportive health care providers (both systems and practitioners) who mitigate treatment burdens can also be seen as supportive resource caravan passageways [12]. However, resource caravan passageways can also obstruct people's resource reservoirs, and in this way people who struggle to protect their resources can be hindered by conditions beyond their control [9]. Hobfoll [11] also emphasized that persons belonging to higher social layers are more likely to have caravan passageways that support or enhance their resources. Thus, although it is considered highly important that patients do self-management work for their chronic conditions [6], motivation, available resources (resource caravans) and external conditions (resource caravan passageways) may influence the extent to which this work is actually done.

One group that seems to do self-management work is persons with food hypersensitivity (FH). (FH is a collective term for all non-toxic adverse reactions to foods, and is also referred to as food allergies and food intolerances [13]). In this study, individuals with FH include all those who report that they are hypersensitive to foods; some of them have received a diagnosis of FH from conventional medicine, others have self-defined or alternative medicine-defined FH. Persons with FH carry out self-management work despite the fact that this work can be socially problematic, and despite sparse health services [14–16]. Indeed, FH is controversial; there have been suggestions that too many people claim to have FH, and there is a possible stigma attached to having a restricted diet [17–19]. Self-management work related to FH may include finding out which foods cause symptoms, purchasing and making foods that do not include symptom-causing components, instructing other persons on the preparation of foods or clarifying the content of meals with other persons, maintaining a nutritious diet despite restrictions, and avoiding a diet that is too restricted.

Our aim is to explore what makes adult women with FH carry out the work of managing their condition. This study is the product of a project that includes only adult women and thus is restricted to this group. Our research will shed light on the health care needs of women with FH and may contribute to the knowledge on self-management among persons with chronic conditions.

Methods

Design and sample

We analyzed 16 qualitative individual interviews of women with FH aged 39–67 years (mean age 49.7 years). MJ conducted the practical work of recruitment, interviewing, and analyzing, in close cooperation with the co-authors. The Norwegian Center for Research Data was notified about the study, as per current standards.

The interviews were semi-structured and were planned and carried out for the initial purpose of illuminating

the nature of the work that goes into managing FH (as described in another article in press [20]). MJ developed the interview guide, and the guide was tested in a pilot interview with a woman with FH. This pilot interview led to some small amendments in the interview guide, as well as some amendments in the interview technique.

However, after the first couple of interviews with study participants, the research team noticed that the interviewees showed a considerable ability to manage their FH. This roused the authors' curiosity, and it was decided that the interviewer should ensure that the analytical question "What is it that makes them manage FH?" was illuminated in the interviews.

The study sample was chosen purposively, with the intention to interview women with and without a diagnosis of FH and with and without other chronic health conditions. Most participants were recruited through acquaintances of MJ or through contacts at The Norwegian Asthma and Allergy Association and The Norwegian Celiac Association. These contacts outside the research team gave potential interviewees information about the study, asked whether they wanted to participate in the study, and asked whether MJ could contact them. This recruitment procedure was chosen to prevent potential interviewees from feeling pressured to participate, under the assumption that a request from someone outside the research team would place less pressure on potential interviewees than a direct request from the researchers. Furthermore, since we placed strong emphasis on the fact that participation was voluntary, women did not have to explain any unwillingness to participate. Thus, we do not know why some women chose not to participate.

In addition to the described recruitment strategy, one woman was recruited through an invitation posted on the Norwegian Asthma and Allergy Associations Facebook page, and one woman self-recruited when she heard about the project topic from MJ.

All scheduled interviews were carried out as planned, except one that was canceled for reasons unrelated to the project. A new participant was recruited to replace this participant.

Data collection and analysis

The interviews were carried out in five different towns in Norway between August and November of 2016. All interviews were conducted face-to-face in an undisturbed, quiet location chosen by the participant; in the interviewees' homes, in the interviewees' place of work, or on the premises of UiT The arctic university of Norway. One interview per participant was conducted, and only the interviewer and the individual interviewee were present.

Before the interviews started, the participant signed a written informed consent form, and all interviews began

with the interviewer asking the participant to describe how she found out that there are food(s) she cannot tolerate. Most participants gave thorough answers to this question, and the interviewer used this information to pose follow-up questions concerning the work of managing FH and what made the participants manage FH. At the end of the interview, the interviewer looked through the interview guide to make sure all topics had been covered. The interviews lasted from 53 to 98 min (mean 67 min), and were audio recorded and transcribed by a professional transcriber. The participants were encouraged to contact the interviewer after the interview if they had anything they wanted to add to the interview, and one participant did so. The participants were not asked to give feedback on the findings.

Before the analysis, the interviews were listened to and read through to allow for familiarization with the data. Then all interviews were read through again, with the focus on exploring what made the women manage FH. During this process, two important answers to this question were discovered: (1) The interviewees showed significant *motivation* to do the work of managing FH, and (2) The interviewees had *ability* to do the work of managing FH. Consequently, further analyses focused on these two aspects.

First MJ read the interviews, noted what motivated each participant, and made a condensation, which is presented in the second part of the results section. COR theory and SDT were used to interpret these findings and understand the participants' motivations.

Secondly, the researchers analyzed what made the participant able to do the work of managing FH. After having read the interviews we had the clear impression that the participants' individual and social resources, as well as external factors, were important to their ability to do self-management work. This aspect is also emphasized in COR theory, and thus we found COR theory concepts of 'resource caravans', 'caravan passageways', and 'resource spirals' to be useful when discussing the findings. SDT was also used to discuss and understand the findings, and SDT's focus on the interrelationship between motivation and the basic psychological needs of autonomy, competence, and relatedness in particular influenced our interpretation of the interviews. We did not use any software in the analysis.

We observed that the main motivators, as well as the factors that made participants able to do the work of managing FH, were mentioned within the first seven interviews, while in the remainder of the interviews these themes were elaborated and illuminated from other angles. This indicates that saturation was achieved within the 16 interviews, which is in line with studies that have concluded that saturation in studies with purposive samples often occur within the first 12 interviews [21].

Results

Characteristics of the participants

Sixteen women with FH aged 39–67 years (mean age 49.7 years) participated in this study. Eight of these women had a diagnosis of FH based on conventional medicine tests (food allergies, celiac disease, and/or lactose intolerance), two had a diagnosis of irritable bowel syndrome, two said that a medical doctor had mentioned that they had or may have irritable bowel syndrome, and four had no diagnosis of FH from conventional medicine (See Table 1). Most of the women with a diagnosis of FH from conventional medicine reported an additional, undiagnosed FH. Furthermore, eight of the women had other chronic health complaints such as diabetes, hypothyroidism, rheumatoid arthritis, fibromyalgia, or asthma/allergies that required daily medication, while the other eight did not have such conditions. The interviewees described FH or symptoms of FH that had lasted for years or decades. Fourteen women reported hypersensitivity to more than one food; most women reported hypersensitivity to common foods like milk, gluten, or wheat.

Nine interviewees had minor children, eight of whom lived with a partner; and seven had adult children, six of whom lived with a partner. Four women had secondary school as their highest completed education, six had a bachelor's degree, and six women had a master's degree.

Motivation

Many interviewees revealed a strong motivation to do self-management work, and this was expressed, among

other things, through an extensive effort to find out which foods caused symptoms, and through the continuous attention they paid to avoid those foods. All participants reported that their physical afflictions or symptoms had persisted for a relatively long period. For some, symptoms began in childhood, for others in adulthood. The most mentioned symptoms were stomach pain, diarrhea, constipation, flatulence, nausea, breathing problems, laxity, low energy, hives, and other skin symptoms. All women had taken the initiative to determine what was causing the symptoms, and after getting advice from others, from health services, from alternative medicine actors, or on their own initiative, they removed one or more foods from their diet, i.e. implemented a restricted diet. After doing this they experienced significant symptom reduction. Some reported that they got rid of their affliction completely, while others experienced improved health and reduced symptoms. The women reported that their main motivation for implementing a restricted diet was to eliminate or reduce physical symptoms they described as uncomfortable or intolerable. Brita (no diagnosis) gave an example of uncomfortable symptoms:

...suddenly I got sick, I got dizzy, I started sweating, I had to get out, and I threw up.

The women also described that the symptoms had negative consequences on work, general energy level, leisure activities, and quality of life, and the wish to avoid these consequences were strong motivators to do self-management work. The desire to work and take care of

Table 1 Participant characteristics

	Diagnosis of food hypersensitivity from conventional medicine	Other chronic conditions	Age	Education level
Dina	Yes, Celiac disease	No	39–49	Master
Eline	Yes, Celiac disease	Yes	50–59	Master
Grethe	Yes, Celiac disease	Yes	50–59	Master
Carina	Yes, Celiac disease and lactose intolerance	Yes	60–67	Secondary
Anna	Yes, Lactose intolerance (and irritable bowel syndrome)	Yes	39–49	Secondary
Helen	Yes, food allergies	No	39–49	Master
Mary	Yes, food allergies	No	39–49	Bachelor
Ruth	Yes, food allergies	No	50–59	Bachelor
Frida	Possible irritable bowel syndrome	No	50–59	Master
Lena	Yes, irritable bowel syndrome	No	39–49	Bachelor
Irene	Possible irritable bowel syndrome	Yes	39–49	Bachelor
Kristina	Yes, irritable bowel syndrome	Yes	60–67	Secondary
Sarah	No	No	39–49	Secondary
Jeanette	No	No	50–59	Bachelor
Nina	No	Yes	50–59	Bachelor
Brita	No	Yes	50–59	Master

children was an especially strong motivator for the interviewees. Jeanette (no diagnosis) verbalized this:

I had symptoms for a while; for half a year to three-quarters of a year, all the food just went straight through me (...) and I decided this had to stop. I was on the toilet 20 to 30 times a day. When you have these symptoms, it is almost impossible to go to work, although I did. I want to go to work (...) So I decided that I have to find a way to function, I have to stay healthy. I have responsibilities, I have children and I have a family.

The symptoms could also lead to shame or stigma, which participants tried to avoid by reducing or avoiding the symptoms. Nina (no diagnosis) exemplified this with a story on how she fainted due to intense stomach pain after having ingested an adverse food. She experienced this as embarrassing:

My stomach hurt so, so much (...) and when we were leaving, I fainted and fell on the floor. That is not a fun thing when you are at a restaurant, and it led to a lot of fuss.

Participants mentioned how stomach problems and diarrhea could lead to flatulence or involuntary defecation, which was experienced as very embarrassing. Furthermore, they emphasized the shame related to stomach troubles, referring to it as an unspeakable topic. One of the interviewees said:

It is difficult to speak about this topic (...) it leaves you vulnerable, and it is very embarrassing.

Some women mentioned additional motivations for implementing a restricted diet. For example, a few participants had experienced threatening allergic reactions. Others, having experienced that removing foods made them healthier, tried to remove other foods as well, hoping that this would further reduce symptoms and improve their health. One interviewee perceived certain alternative diets to be particularly healthy and used a restricted diet to avoid weight gain. Some of the women with celiac disease said that a part of their motivation for implementing a gluten-free diet was to avoid sequela.

In summary, the participants said that the main driving force for removing foods from their diet was to avoid symptoms, because these symptoms were uncomfortable and had negative consequences. However, interviewees who did not have strong symptoms showed a lower motivation to consistently implement a restricted diet compared to those with strong symptoms.

Resources used in self-management work

As mentioned, many interviewees experienced uncomfortable symptoms. They were highly motivated and expended great effort to avoid these symptoms. In this process, their individual resources, often in combination with available social resources, were crucial in finding out what foods caused symptoms and to manage their FH. This was true regardless of whether the women received a diagnosis or whether they had contact with conventional health services or alternative medicine. Interviewees with a diagnosis of celiac disease from conventional medicine received information from health services at the time of diagnosis about how to manage this condition. However, when they experienced new symptoms later on, they used individual resources combined with advice from family or friends to find out what was causing them. Grethe (celiac disease) said:

It was a period in which I could not understand why I was feeling ill (...) So I tried to find out what was making me feel ill, as I have done several times. (...)

When faced with these new symptoms, Grethe went through what she had eaten in the preceding days, and combined this with information from a patient organization and from an acquaintance with celiac disease. Through this process, she understood that wheat starch had caused the symptoms.

Interviewees who had a diagnosis of food allergy or lactose intolerance from conventional medicine also had contact with health services at the time of diagnosis, but after that they used individual and social resources to find out what concrete products and meals to avoid, and which to eat to ensure a varied diet. In this process, they described personal interests in foods and tips from friends and family as useful. This was verbalized by Anna (lactose intolerance):

I am interested in food (...) and I have some friends who...we talk a lot about food and give each other advice.

Those who did not have any of the above diagnoses from conventional medicine, but received help from actors in alternative medicine, combined this help with individual and social resources. For example, an alternative medicine clinic advised Jeanette (no diagnosis) to start a very restricted diet and then to gradually reintroduce foods. Furthermore, a family member supported her and helped her to interpret tests she underwent to assess whether she was receiving the correct amount of nutrients despite the restricted diet. In addition, Jeanette used her own time and effort to carry out the very restricted diet, and to evaluate how she reacted to newly reintroduced foods.

Some interviewees did not receive help from health services or from alternative medicine. Instead they mainly relied on their own experiences and resources. Some individual resources that were useful were interest in food, food-related education, and a range of problem-focused strategies, such as planning in advance and bringing one's own food.

One individual resource that seemed crucial to self-management work was the ability to critically assess the advice of others. Interviewees described that some alternative medicine actors recommended diets that were too comprehensive. Other interviewees described that advice from acquaintances was characterized by confusion between FH and other reasons for having a special diet. However, several interviewees critically assessed this information, chose what they considered relevant for them, and thus avoided diets that were too restrictive. Nina (no diagnosis) gives an example:

I have heard about people who go to a homeopath with one small problem, and then they tell you that you react to 30 foods (...) So I avoided this [going to homeopaths].

Interviewees also reported going through individual processes of reorientation, which resulted in the realization that they had to put in time and effort to manage their FH. Further, interviewees described individual, emotion-focused strategies that made it easier to live with the restricted diet, like comparing their situation with that of others who were worse-off, or changing their focus from food to other aspects of their life.

Interviewees who had persons competent in FH in their close network clearly took advantage of this. These interviewees received advice about how to ensure proper nourishment despite the restricted diet. Furthermore, they could ask these network members why new symptoms had appeared and immediately receive an answer, while others spent much more time finding relevant information. Carina (celiac disease and lactose intolerance) gave an example of how family can contribute to clarifying which foods cause symptoms:

But 2 years ago I started to have stomach trouble (...) and I never got well. And my [family member], who is lactose intolerant, said I should try to remove lactose (...) I did, and I got well.

Scarcity of the above-mentioned individual resources, combined with a complex FH and little help from others, seemed to make the work of managing FH challenging, including finding out which foods caused symptoms and what foods and dishes to eat. Further, those who were unsure about which foods caused symptoms did not implement a restricted diet as consistently as

those who were sure about this. Some interviewees also described a reduced ability to critically assess the advice of others, which led to a diet that was a mixture of FH restrictions and other dietary restrictions, which may lead to unnecessary restrictions.

Some interviewees mentioned explicitly how resource scarcity influenced the management of their FH. One example is Mary (food allergies) who said that, because of her lack of energy, it took her a long time to change her diet and find concrete dishes she could eat. Moreover, she often did not have the energy to make varied dishes:

Sometimes I just have to go through the hassle [of making time-consuming dishes] (...) but I do not often have the energy. Usually I make dishes that do not require much effort. (...) So it is the same few dishes.

External factors that influenced self-management work

The interviews indicated that external factors also influenced self-management work. Some participants reported that they probably had FH for years or decades, but since it was not something they had previously thought about, the symptoms remained unexplained for years. Increased public awareness of FH in the last years contributed to the thought that their symptoms might be caused by FH, which for some was confirmed by conventional medicine. This also led to a restricted diet, and the reduction or removal of symptoms. Thus, the awareness of the phenomenon of FH could be perceived as crucial to carrying out self-management work. The participants also said that other reasons for dieting had received increased attention, and their FH was associated and mixed together with these other diets. Some mentioned that their FH was met with disbelief and criticism; that it was not taken seriously, was perceived as a fad, was linked to hysteria or stress, or was seen as a psychological problem, and participants found this to be stigmatizing.

In general, the interviewees communicated the attitude that meals should be shared, and some expressed the desire not to bother those who made food for them with their demanding restrictions. Some said they wanted to eat what they were offered, just like the others at the table, and some mentioned that they were excluded from certain social situations because of their restricted diet. In short, some interviewees did not want to break with the social expectations of the meal; instead they wanted to take part in the meal, and some interviewees ate foods they could not tolerate to avoid breaking with these expectations. However, this only applied to those with fairly weak reactions to foods. Helen (allergies) is an example of this:

“So I don't mention [the FH], when I am at restaurants. There I eat foods that I would not eat at home.”

Participants also described increased knowledge of FH, which made self-management work easier. However, the interviewees reported varying knowledge levels among staff in restaurants and cafes, which required the participants to assess whether the person they were interacting with had sufficient competence.

The selection of foods and dishes can also be seen as both facilitating and complicating the work of managing FH. Participants with a hypersensitivity to gluten, wheat, or lactose saw the increased selection of gluten- or lactose-free goods as an advantage. Some also found it advantageous that international dishes with less milk and gluten had entered the Norwegian diet. However, the introduction of new foods in the Norwegian diet gave some interviewees new allergies, and some pointed to an increased tendency to put ‘everything in everything’, which made it more difficult to find out whether the foods they could not tolerate were included in dishes. Some mentioned that increased labeling was an advantage, although some also mentioned examples of over-labeling. Participants mentioned that courses, information, and counseling organized by patient organizations facilitated the work of managing FH. They also mentioned that carrying out a restricted diet was costly, but none said that this stopped them from implementing the diet.

We found no clear relationship between education level and the resources and self-management described in this small sample. However, competing priorities were a factor that made the self-management work difficult for some, especially the priorities of work and small children. Some interviewees expressed that dealing with work and children made it difficult to do the work of finding out what foods they could not tolerate, what concrete foods and dishes to eat, or to implement a varied diet. Frida (possible irritable bowel syndrome), who has a very restricted FODMAP diet, gave an example of how reintroducing foods can cause significant symptoms that are incompatible with work and taking care of children, and thus her diet remains very restricted:

According to the (FODMAP) diet, you are supposed to reintroduce [foods], but you have to have an ocean of time to do this, which I do not have.

Discussion

The interviewees did self-management work because they were highly motivated, and this motivation was expressed through, among other things, being continuously alert to avoid foods they did not tolerate. Important motivators included the uncomfortable symptoms that resulted from consuming some foods, which had negative consequences on their energy, work, and family, or could bring shame or embarrassment.

Individual resources also played a key role in self-management work. Important individual resources were the ability to critically assess advice from others and chose what was relevant, and the realization that it would take time and effort to manage FH. Other individual resources were a broad range of problem- and emotion-focused strategies. Those who had a social network that contained people with relevant knowledge clearly took advantage of this. They received advice about how to ensure a nutritious diet despite the restrictions, and it took them less time to find out which foods caused symptoms. Scarcity of individual and social resources seemed to make it more challenging to do self-management work, and to find out which foods caused symptoms. Lack of competence about what foods that caused symptoms reduced participants’ motivation to consistently implement a restricted diet.

One external factor that was important for the management of FH was the increased public awareness of these conditions. Hindrances to this management were competing priorities, wanting to take part in meals like everyone else, and the stigma related to having a special diet. However, the economic costs of a special diet did not hinder participants from implementing it.

Many participants described uncomfortable symptoms, such as gastrointestinal symptoms. For some, these symptoms appeared a short time after they ingested adverse foods. The wish to avoid these symptoms seemed to be an important motivator for persons with FH to conduct self-management work. This is in contrast to other studies that reported that lack of immediate symptoms reduces motivation to conduct the work of managing a chronic condition [22, 23].

The participants also described that the symptoms could have negative consequences on their lives, family, and work, which they wanted to avoid. The wish to stay healthy and take care of family could be seen as intrinsic aspirations, which produce high-quality motivation according to SDT [6]. This is also in line with COR theory, which suggests that people strive to take care of and retrieve the things that they centrally value, such as health, work, and family [9]. In addition to this individual motivation to retrieve health, it has also been argued that, while in the past health was considered something that was given to us, the idea that health is an individual responsibility has become more and more prevalent in the last years [24, 25]. In other words, the fear of losing things that one really values may be a strong motivator, which may be supported by the expectation that one should take care of one’s own health.

Some interviewees also seemed to be motivated to do self-management work due to their wish to avoid embarrassment or shame. Giddens calls shame the ‘negative side of an individual’s motivational scheme’ [26:84], and

other research has also indicated that embarrassment and shame have the potential to motivate [27]. The avoidance of shame, or doing actions to enhance one's ego or pride, is also described in SDT as a relatively strong motivating force [28]. Thus, it is probable that persons with other gastrointestinal health conditions may be motivated to do self-management in order to avoid shame or embarrassment. On the other hand, some interviewees did eat adverse foods when they ate with others, which can be seen as an attempt to avoid the stigma that may be connected to a restricted diet. This is in line with studies that have shown that stigma or shame can be obstacles to self-management work, like sticking to a restricted diet [19].

In summary, the wish to avoid uncomfortable symptoms and their consequences were strong motivational forces. However, one may speculate whether these motivators are so strong that they sometimes lead to a diet that is too restricted. Larger access to competent diagnostic help from health services may reduce the extent of this phenomenon.

The interviewees presented individual strategies like problem-focused coping strategies, emotion-focused strategies, and realization of necessary work, which also have been described as enhancing self-management in studies of other chronic conditions [12, 29]. However, individual and social resources seemed to be more crucial for women with FH compared to other chronic conditions, and this may be related to the sparse health services available to adult persons with FH [15, 16].

One of the individual resources that interviewees had, to a larger or lesser extent, was the ability to critically assess the advice of others. Assessment like this may be important for persons with chronic conditions in general. However, this assessment may be especially challenging for persons with conditions like FH, because there are many FH conditions, as well as other reasons for having a special diet [15, 30], and these can be mixed together. Furthermore, health services have varying competencies, and conventional health services and alternative medicine can give conflicting information [15, 17, 18].

This study showed that having knowledge about which foods caused symptoms was an important motivator for consistently sticking to a restricted diet. This is in accordance with SDT, which emphasizes that competence is important for high-quality motivation [7]. Furthermore, those who had sufficient individual and social resources seemed to be able to acquire this competence more easily, which is in accordance with COR theory [11]. This may also apply to other groups of people with chronic conditions: available individual and social resources influence whether they gain knowledge, which in turn influences their degree of motivation to do self-management work. Thus, resources may enhance self-

management work both directly and indirectly, via increased access to competence that enhances motivation.

In agreement with previous studies [29], a factor that clearly influenced participants' capacity to do self-management work was competing priorities (such as work and small children). This indicates that not only the amount of resources, but also to what degree these resources are available, influence one's capacity to do self-management work.

Using Hobfoll's [9] terms, material, individual, and social resources can be seen as 'resource caravans,' while the environmental conditions that facilitate or hinder an individual are referred to as 'caravan passageways'. One important factor that seemed to expand caravan passageways in our study was an increased public awareness of FH. Factors that seemed to narrow the caravan passageway and make the work of managing FH more demanding were the stigma related to having a restricted diet and the social expectations related to meals. Thus, while other studies reported that 'caravan passageways' included factors like safety, school quality, and relatively tangible conditions [9], in our study caravan passageways were described as being related to attitudes, perceptions, and ways of thinking about food and FH.

According to SDT, it is not only competence, but also autonomy and relatedness that are important for high-quality motivation [7, 8]. The interviewees presented a relatively high degree of autonomy, partly because they assessed and chose the advice that they found most useful. However, the fact that some interviewees chose to eat adverse foods may be related not only to a wish to avoid stigma, but also to a need to be part of the meal like everyone else at the table, which can be seen as ensuring the basic need of relatedness. Breaking with the expectations of the meal may obstruct the bonding and intimacy that takes place when sharing a meal [19, 31], and may thus threaten relatedness. The wish to attend to one's basic needs probably affects self-management work in other patient groups as well. For example, receiving a self-management arrangement from health services may reduce a patient's feeling of autonomy. Further, other conditions that require a diet, such as diabetes, may threaten the need for relatedness.

As indicated, some interviewees had the individual and social resources necessary to manage their FH, and thus hinder a negative resource cycle [11]. Others did not have these resources, and/or competing priorities kept them from doing self-management work. Based on this, one may conclude that some persons with FH do not need help from health services, while others may benefit from such help. Help from health services should be based on SDT – principles ensuring competence, relatedness, and autonomy [7]. Relatedness can be ensured through showing understanding and respect. For women

with FH, one important competence is knowing what foods to avoid and what foods and dishes to eat.

As described, some participants had the resources necessary to manage their FH. However, management of FH required that participants were constantly alert, and participants also experienced negative reactions towards their restricted diet from others. Studies on persons with food allergies and their families indicate that both of these factors can compromise quality of life [32, 33]. This indicates that even though some persons are able to manage their FH successfully and maintain their health relatively well, they may still experience a reduced quality of life because they have to be constantly alert and deal with negative reactions from others.

One limitation of the study may be that the interviews were designed to focus primarily on illuminating the nature of the work that goes into managing FH. Thus, some information, for example on motivation and resources used, may not have come forth. Further, the limitation to women aged 39–67 removed the opportunity to illuminate what makes men and younger women with FH do self-management work.

One aspect which can be seen as a weakness with the study, and which have to be taken into consideration when reading the present study, is the fact that the sample had a considerably higher education level than the average Norwegian population [34]. This high education level indicates that the sample had access to more resources than the average population [11], including resources that can be used to manage FH. One cannot rule out that a sample of women with a lower education level may have revealed somewhat different findings. For example, none of the participants reported economical costs as a hindrance to implementing a restricted diet. However, this finding may not necessarily apply to other samples.

Conclusions

The analysis showed that women with FH carried out the work of managing their condition because they were highly motivated. The wish to avoid uncomfortable symptoms, as well as the wish to avoid the negative consequences of these symptoms, were the most important motivators. In addition, some symptoms led to shameful experiences, and the wish to avoid these experiences can be motivating. Further, the analysis showed that self-management was largely dependent on the person's individual and social resources. This may be a result of sparse health services, conflicting information, and mixing FH together with other reasons for having a special diet. Some women with FH had the individual and social resources necessary to manage their conditions, and thus may not need health services. Others may not have the necessary resources, or may have significant competing

priorities, and these individuals may need help from health services. This help may ensure that the basic needs of competence and relatedness are covered. More concretely, improving competence may entail assisting women in determining which foods cause symptoms, which may contribute to avoiding unnecessary restrictions. It may also include assistance in find out what foods and dishes to eat, and assistance in ensuring a nutritious diet. Improving relatedness, through showing understanding and respect, may compensate for any loss of relatedness that people with FH may experience in relation to meals.

Covering the basic needs of competence and relatedness may also contribute to self-management among persons with other chronic conditions. On the other hand, a person's wish to fulfil these basic needs can become an obstacle to self-management work. For example, patients may break with recommended diets to take part in the relatedness offered by sharing a meal.

The wish to avoid uncomfortable symptoms will probably motivate people with chronic conditions in general to conduct self-management work. However, this indicates that those without immediate, uncomfortable symptoms may have lower motivation. The wish to avoid shame can be a general motivator to conduct self-management work, but it can also be an obstacle to this work. Individual and social resources increase a person's capacity to do self-management work directly and indirectly, because people with these resources are able to gain knowledge that increases their motivation.

Abbreviations

COR theory: Conservation of resources theory; FH: Food hypersensitivity; REC: Regional Committee for Medical and Health Research Ethics; SDT: Self-Determination theory

Acknowledgements

The authors want to express gratitude to the interviewees and those who have helped us recruit interviewees. We also want to thank Ms. Trudy Perdrix-Thoma for language review prior to submission.

Authors' contributions

MJ, AO, TB and BA have made substantial contributions in the conception and design of the study. MJ carried out the interviews in close cooperation with AO, TB and BA. MJ did the analysis, and BA and AO made substantial contributions to this work. MJ wrote the first draft, and AO, TB and BA substantively revised the manuscript. All authors have read and approved the final manuscript.

Funding

The study is funded by the Department of Community Medicine, UiT The Arctic University of Norway (grant agreement 4025). The funders had no role in study design, data collection, analysis of data, or preparation of the manuscript.

Availability of data and materials

The qualitative interviews cannot be shared, since participant consent for this was not obtained.

Ethics approval and consent to participate

Before the study started and in line with procedures, the authors sent a remit assessment to the Regional Committee for Medical and Health

Research Ethics (REC) North. REC North is administratively organized under UiT The Arctic University of Norway. REC North responded that the present study did not require approval from REC (2014/1565). In addition, and also in line with procedures, a notification form was submitted to The Norwegian Centre for Research Data, and the study was approved (project number 40138). All participants gave written consent to participate in the study, and all procedures in the study were in full compliance with the ethical standards of The Norwegian Centre for Research Data and with the 2004 Helsinki Declaration and its later amendments.

Consent for publication

Not applicable.

Competing interests

The authors state that they have no competing interests.

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Received: 1 December 2017 Accepted: 10 June 2019

Published online: 08 July 2019

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Appendix 1

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KVINNER OG KREFT

Orientering om undersøkelsen

Du samtykket i 1991 og 1998 til å fylle ut et spørreskjema som du mottok i posten - Kvinner og Kreft. Spørreskjemaet tok opp en rekke forhold knyttet til ditt liv, som barnefødsler, p-pillebruk, kosthold, røyking og sosiale forhold. Formålet med undersøkelsen var å se om disse forhold har betydning for utvikling av kreft hos kvinner. Resultatene vil bli publisert i dagspressen og i internasjonale fagtidsskrifter. Ansvarlig for undersøkelsen er professor Eiliv Lund.

Vi retter nå en ny forespørsel til deg om du nok en gang vil besvare det vedlagte spørreskjemaet. Begrunnelsen for å kontakte deg på ny er at mange av de spørsmålene du besvarte sist gjaldt levevaner som vi vet endrer seg med alderen. De fleste spørsmålene vil dreie seg om årene siden siste utfylling.

Undersøkelsen er tilrådd av Regional komité for medisinsk forskningsetikk i Nord-Norge. Adressen din henter vi fra det sentrale personregister ved hjelp av Statistisk Sentralbyrå. Som forrige gang inneholder spørreskjemaet kun løpenummer uten annen identifikasjon, for derved å gi dine opplysninger et bedre personvern.

Med noen års mellomrom frem til år 2034 vil vi sammenholde opplysningene som du har gitt i undersøkelsen med opplysninger fra Kreftregisteret og Dødsårsaksregisteret. Ved å studere materialet på nytt, håper vi å finne ut årsakene til at noen kvinner får kreft. Alle opplysningene fra spørreskjemaene og registrene vil bli behandlet konfidensielt og etter de regler Datatilsynet har gitt i sin tillatelse.

Det er frivillig om du vil være med i undersøkelsen. Du kan senere trekke deg uten begrunnelse og uten at det vil få noen konsekvenser for deg. Opplysninger du har gitt kan du be om å få slettet.

Vi vil be deg om å besvare det vedlagte spørreskjemaet så riktig som mulig. Dersom ingen av de oppgitte svaralternativ dekker din situasjon, sett kryss for det alternativet som ligger nærmest. Gi eventuelt merknader eller tilleggsopplysninger i skjemaet. Vi spør også alle som deltar om tillatelse til fornyet kontakt om noen år i form av et liknende spørreskjema.

Vi vil senere kontakte en del av deltakerne for å få tatt en blodprøve. Det vil skje hos nærmeste lege og være gratis. Noen kvinner vil også bli forespurt om å delta i et kostholdsintervju over telefon.

For spørsmål om bruk av hormoner i overgangsalderen finner du bilder i denne brosjyren som skal være et hjelpemiddel (brosjyren skal ikke returneres). Spørreskjemaet sendes tilbake i vedlagte konvolutt som vi betaler svarporto for.

Med hilsen

Eiliv Lund
professor dr.med.

Bente A. Augdal
prosjektmedarbeider

HØST-2004

Du kan finne mer informasjon om "Kvinner og Kreft" på våre nettsider: www.ism.uit.no/kk

KVINNER OG KREFT

Hvis du samtykker i å være med, sett kryss for JA i ruten ved siden av.

Dersom du ikke ønsker å delta kan du unngå puring ved å sette kryss for NEI og returnere skjemaet i vedlagte svarkonvolutt.

Vi ber deg fylle ut spørreskjemaet så nøye som mulig.

Skjemaet skal leses optisk. Vennligst bruk blå eller sort penn. Du kan ikke bruke komma, forhøy 0,5 til 1. Bruk blokkbokstaver.

Med vennlig hilsen
Eiliv Lund

KONFIDENSIELT

Jeg samtykker i å delta i JA
spørreskjemaundersøkelsen NEI

Overgangsalder

Har du regelmessig menstruasjon fremdeles?

- Ja
 Har uregelmessig menstruasjon
 Vet ikke (menstruasjon uteblitt pga. sykdom o.l.)
 Vet ikke (bruker hormonpreparat med østrogen)
 Nei

+

Hvis Nei;

- har den stoppet av seg selv?
 har du operert vekk eggstokkene?
 har du operert vekk livmoren?
 annet?

Alder da menstruasjonen opphørte

Hvor gammel var du første gang du brukte østrogen-tabletter/plaster?

Bruker du tabletter/plaster nå? Ja Nei

UTFYLLENDE SPØRSMÅL TIL ALLE SOM HAR BRUKT PREPARATER MED ØSTROGEN I FORM AV TABLETTER ELLER PLASTER FRA 1998 OG FREM TIL I DAG.

Har du svart «ja», ber vi deg utdype dette nærmere ved å svare på spørsmålene nedenfor. For hver periode med sammenhengende bruk av samme hormonpreparat håper vi du kan si oss hvor gammel du var da du startet, hvor lenge du brukte det samme hormonpreparatet og navnet på dette. Dersom du har hatt opphold eller skiftet merke skal du besvare spørsmålene for en ny periode. Dersom du ikke husker navnet på hormonpreparatet, sett «usikker». For å hjelpe deg til å huske navnet på hormonpreparatene ber vi deg bruke den vedlagte brosjyre som viser bilder av hormonpreparater som har vært solgt i Norge. Vennligst oppgi også nummer på hormontabletten/plasteret som står i brosjyren.

Graviditeter, fødsler og amming

Har du noen gang vært gravid? Ja Nei

Hvis Ja; hvor mange barn har du født i alt

Hvor gammel var du ved siste fødsel?

+

P-pillebruk

Har du brukt p-piller eller minipiller? Ja Nei

Hvis ja, hvor mange år har du brukt p-piller i alt?

Bruker du p-piller nå? Ja Nei

Bruk av hormonpreparater med østrogen i overgangsalderen

Har du noen gang brukt østrogen-tabletter/plaster? Ja Nei

Hvis Ja; hvor mange år har du brukt østrogen-tabletter/plaster i alt?

Periode	Alder ved start	Brukt samme hormontablett/plaster/sammenhengende fra 1998		Nr.	Navn på hormontablett/plaster/ (se brosjyre)
		år	måned		
1.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
2.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
3.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
5.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

+

Østrogenpreparat til lokal bruk i skjeden

Har du noen gang brukt østrogen-krem/stikkpille? Ja Nei

Hvis Ja; bruker du krem/stikkpille nå? Ja Nei

Hormonspiral

Har du noen gang brukt hormonspiral (Levonova)? Ja Nei

Hvis Ja; hvor mange hele år har du brukt hormonspiral i alt?

Hvor gammel var du første gang du fikk innsatt hormonspiral?

Bruker du hormonspiral nå? Ja Nei

Selvopplevd helse

Oppfatter du din egen helse som; (Sett ett kryss)

Meget god God Dårlig Meget dårlig

Sykdom

Har du eller har du hatt noen av følgende sykdommer?

(sett ett eller flere kryss)

	Ja	Nei	Hvis ja: Alder ved start
Kreft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Høyt blodtrykk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Hjertesvikt/hjertekrampe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Hjerteinfarkt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Slag	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Sukkersyke (diabetes)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Depresjon (oppsøkt lege)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Hypothyreose/lavt stoffskifte	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

For følgende tilstander ber vi deg krysse av for hvilket år tilstanden oppsto første gang.

	før 98	98	99	00	01	02	03
Muskelsmerter (myalgi)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fibromyalgi/Fibrositt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kronisk tretthetssyndrom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ryggsmerter ukjent årsak	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nakkeslengskade	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Osteoporose (b.skjørhet)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brudd							
Underarmen (håndledd)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lårhalsen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ryggvirvel (kompresjon)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Andre legemidler

Bruker du noen av disse legemidlene daglig nå?

Fontex, Fluoxetin Ja Nei

Cipramil, Citalopram, Desital Ja Nei

Seroxat, Paroxetin Ja Nei

Zoloft Ja Nei

Fevarin Ja Nei

Cipralext Ja Nei

Hvis Ja; hvor lenge har du brukt dette legemidlet sammenhengende? Måneders År

Har du benyttet noen av disse legemidlene tidligere? Ja Nei

Hvis Ja; hvor lenge har du benyttet disse legemidlene i alt? År

Høyde og vekt

Hvor høy er du?(i hele cm)

Hvor mye veier du i dag?(i hele kg)

Hvor mye veide du da du var 18 år?(i hele kg)

Kroppstype i 1. klasse. (Sett ett kryss)

Veldig tynn Tynn Normal Tykk Veldig tykk

Røykevaner

Har du i løpet av livet røykt mer enn 100 sigaretter til sammen? Ja Nei

Hvis Ja, ber vi deg fylle ut for de siste fem årene hvor mange sigaretter du i gjennomsnitt røykte pr. dag i denne perioden.

Antall sigaretter pr. dag

0 1-4 5-9 10-14 15-19 20-24 25+

Hvor gammel var du da du tok din første sigarett?

Røyker du daglig nå? Ja Nei

Hvis Nei, hvor gammel var du da du sluttet?

Røykte noen av dine foreldre da du var barn? Ja Nei

Hvis Ja, hvor mange sigaretter røykte de til sammen pr. dag? (antall)

Brystkreft i nærmeste familie

Har noen nære slektninger hatt brystkreft?

	Ja	Nei	Vet ikke	Alder ved start
Datter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Mor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Søster	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

Mammografiundersøkelse

Har du vært til undersøkelse av brystene med mammografi

Ja Nei

Hvis Ja;

hvor gammel var du første gangen? (hele år)

Hvor mange ganger har du vært undersøkt?

- etter invitasjon fra Mammografiprogrammet
- etter henvisning fra lege
- uten henvisning fra lege

Fysisk aktivitet

Vi ber deg angi din fysiske aktivitet etter en skala fra svært liten til svært mye ved 14 års alder, ved 30 års alder og i dag. Skalaen nedenfor går fra 1-10. Med fysisk aktivitet mener vi både arbeid i hjemmet og i yrkeslivet samt trening og annen fysisk aktivitet som turgåing ol.

Alder	Svært lite					Svært mye				
14 år	1	2	3	4	5	6	7	8	9	10
30 år	1	2	3	4	5	6	7	8	9	10
I dag	1	2	3	4	5	6	7	8	9	10

Hvor mange timer pr. dag i gjennomsnitt går eller spaserer du utendørs?

	sjelden/ aldri	mindre enn 1/2 time	1/2-1 time	1-2 timer	mer enn 2 timer
Vinter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vår	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sommer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Høst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor mange trapper (hele etasjer) går du i gjennomsnitt pr. dag

For hver av følgende aktiviteter du deltar i, ber vi deg oppgi hvor mange minutter pr. dag du bruker i gjennomsnitt til hver av aktivitetene.

Aktivitet	Minutter:			
	Vinter	Vår	Sommer	Høst
Se på TV	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Lesing	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Håndarbeid	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Hagearbeid	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Dusj/bad/egenpleie	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Trening/jogging	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Sykling	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Hvor mange hele timer pr. dag bruker du på arbeidsplassen i gjennomsnitt til å

Timer:

- Sitte
- Stå
- Gå
- Løfte
- Tunge løft/pleie

Kosthold

Påvirker noen av følgende forhold kostholdet ditt?

(sett gjerne flere kryss)

- Er vegetarianer/veganer
- Spiser ikke norsk kost til daglig
- Har allergi/intoleranse
- Kronisk sykdom
- Har anoreksi
- Har bulimi
- Prøver å gå ned i vekt
- Lav glykemisk mat

Vi er interessert i å få kjennskap til hvordan kostholdet ditt er vanligvis. Kryss av for hvert spørsmål om hvor ofte du i gjennomsnitt siste året har brukt den aktuelle matvaren, og hvor mye du pleier å spise/drikke hver gang.

Drikke

Hvor mange glass melk drikker du vanligvis av hver type? (Sett ett kryss pr. linje)

	aldri/sjelden	1-4 pr. uke	5-6 pr. uke	1 pr. dag	2-3 pr. dag	4+ pr. dag
Helmelk (søt, sur)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lettmelk (søt, sur)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ekstra lettmelk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skummet (søt, sur)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor mange kopper kaffe/te drikker du vanligvis av hver sort? (Sett ett kryss for hver linje)

	aldri/sjelden	1-6 pr. uke	1 pr. dag	2-3 pr. dag	4-5 pr. dag	6-7 pr. dag	8+ pr. dag
Kokekaffe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Traktekaffe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pulverkaffe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Svart te	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Grønn te	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Bruker du følgende i kaffe eller te:

	Kaffe		Te	
Sukker (ikke kunstig søtstoff)	<input type="checkbox"/> Ja	<input type="checkbox"/> Nei	<input type="checkbox"/> Ja	<input type="checkbox"/> Nei
Melk eller fløte	<input type="checkbox"/> Ja	<input type="checkbox"/> Nei	<input type="checkbox"/> Ja	<input type="checkbox"/> Nei

Hvor mange glass vann drikker du vanligvis?

(Sett ett kryss for hver linje)

	aldri/sjelden	1-6 pr. uke	1 pr. dag	2-3 pr. dag	4-5 pr. dag	6-7 pr. dag	8+ pr. dag
Springvann/ flaskevann	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor mange glass appelsinjuice, saft og brus drikker du vanligvis? (Sett ett kryss for hver linje)

	aldri/sjelden	1-3 pr. uke	4-6 pr. uke	1 pr. dag	2-3 pr. dag	4+ pr. dag
Appelsinjuice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annen juice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Saft/brus med sukker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Saft/brus sukkerfri	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Yoghurt/kornblanding

Hvor ofte spiser du yoghurt (1 beger)? (Sett ett kryss)

- Aldri/sjelden 1 pr. uke
 2-3 pr. uke 4+ pr. uke

Hvor ofte spiser du kornblanding, havregryn eller müsli? (Sett ett kryss)

- Aldri/sjelden 1-3 pr. uke
 4-6 pr. uke 1 pr. dag

Brødmat

Hvor mange skiver brød/rundstykker og knekkebrød/skonrokker spiser du vanligvis?

(1/2 rundstykke = 1 brødskive) (Sett ett kryss for hver linje)

	aldri/sjelden	1-4 pr. uke	5-7 pr. uke	2-3 pr. dag	4-5 pr. dag	6+ pr. dag
Grovt brød	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kneipp/halvfint	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fint brød/baguett	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Knekkebrød o.l.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I neste spalte er det spørsmål om bruk av ulike påleggstyper. Vi spør om hvor mange brødskiver med det aktuelle pålegget du pleier å spise. Dersom du også bruker matvarene i andre sammenhenger enn til brød (f. eks. til vafler, frokostblandinger, grøt), ber vi om at du tar med dette når du besvarer spørsmålene.

På hvor mange brødskiver bruker du? (Sett ett kryss pr. linje)

	Aldri/sjelden	1-3 pr. uke	4-6 pr. uke	1 pr. dag	2-3 pr. dag	4+ pr. dag
Syltetøy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brunost, helfet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brunost, halvfet/mager	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hvitost, helfet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hvitost, halvfet/mager	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kjøttpålegg, Leverpostei	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rekesalat, italiensk o.l.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

På hvor mange brødskiver pr. uke har du i gjennomsnitt siste året spist? (Sett ett kryss pr. linje)

	Aldri/sjelden	1 pr. uke	2-3 pr. uke	4-6 pr. uke	7-9 pr. uke	10+ pr. uke
Makrell i tomat, røkt makrell	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kaviar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sild/Ansjos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Laks (gravet/røkt)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annet fiskepålegg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hva slags fett bruker du vanligvis på brødet? (Sett gjerne flere kryss)

- Bruker ikke fett på brødet
 Smør
 Hard margarin (f. eks. Per, Melange)
 Myk margarin (f. eks. Soft, Vita, Solsikke)
 Smørblandet margarin (f.eks. Bremyk)
 Brelett
 Lettmargarin (f. eks. Soft light, Letta, Vita Lett)
 Middels lett margarin (f. eks. Olivero, Omega)

Dersom du bruker fett på brødet, hvor tykt lag pleier du å smøre på? (En kuvertpakke med margarin veier 12 gram).

(Sett ett kryss)

- Skrapet (3 g) Tynt lag (5 g)
 Godt dekket (8 g) Tykt lag (12 g)

Frukt og grønnsaker

Hvor ofte spiser du frukt? (Sett ett kryss pr. linje)

	aldri/sjelden	1-3 pr. mnd.	1 pr. uke	2-4 pr. uke	5-6 pr. uke	1 pr. dag	2+ pr. dag
Epler/pærer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appelsiner o.l.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Banener	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annen frukt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor ofte spiser du ulike typer grønnsaker?

(Sett ett kryss pr. linje)

	aldri/ sjelden	1-3 pr.mnd.	1 pr.uke	2 pr.uke	3 pr.uke	4-5 pr.uke	6-7 pr. uke
Gulrøtter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kål	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kålrot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brokkoli/blomkål	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blandet salat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tomat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Grønnsak- blanding (frossen)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Løk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Andre grønnsaker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For de grønnsakene du spiser, kryss av for hvor mye du spiser hver gang. (Sett ett kryss for hver sort)

Gulrøtter	<input type="checkbox"/>	1/2 stk	<input type="checkbox"/>	1 stk	<input type="checkbox"/>	1 1/2 stk	<input type="checkbox"/>	2+ stk.
Kål	<input type="checkbox"/>	1/2 dl	<input type="checkbox"/>	1 dl	<input type="checkbox"/>	1 1/2 dl	<input type="checkbox"/>	2+ dl
Kålrot	<input type="checkbox"/>	1/2 dl	<input type="checkbox"/>	1 dl	<input type="checkbox"/>	1 1/2 dl	<input type="checkbox"/>	2+ dl
Brokkoli/ blomkål	<input type="checkbox"/>	1-2 buketter	<input type="checkbox"/>	3-4 buketter	<input type="checkbox"/>	5+ buketter		
Blandet salat	<input type="checkbox"/>	1 dl	<input type="checkbox"/>	2 dl	<input type="checkbox"/>	3 dl	<input type="checkbox"/>	4+ dl
Tomat	<input type="checkbox"/>	1/4 stk	<input type="checkbox"/>	1/2 stk	<input type="checkbox"/>	1stk	<input type="checkbox"/>	2+ stk
Grønnsak- blanding	<input type="checkbox"/>	1/2 dl	<input type="checkbox"/>	1 dl	<input type="checkbox"/>	2 dl	<input type="checkbox"/>	3+ dl

Hvor mange poteter spiser du vanligvis (kokte, stekte, mos)? (Sett ett kryss)

- Spiser ikke/spiser sjelden poteter 1-4 pr. uke
 5-6 pr. uke 1 pr. dag 2 pr. dag
 3 pr. dag 4+ pr. dag

Ris, spaghetti, grøt, suppe

Hvor ofte bruker du ris og spaghetti/makaroni?

(Sett ett kryss pr. linje)

	aldri/ sjelden	1-3 pr. mnd.	1 pr. uke	2 pr. uke	3+ pr.uke
Ris	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spagetti, makaroni, nudler	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor ofte spiser du grøt? (Sett ett kryss pr. linje)

	aldri/ sjelden	1 pr. mnd.	2-3 pr. mnd.	1 pr. uke	2-6 pr. uke	1+ pr. dag
Risengrynsgrøt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annen grøt (havre o.l.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor ofte spiser du suppe?

(Sett ett kryss pr. linje)

	aldri/ sjelden	1-3 pr. mnd.	1 pr. uke	2 pr. uke	3+ pr.uke
Som hovedrett	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Som forrett, lunsj eller kveldsmat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Fisk

Vi vil gjerne vite hvor ofte du pleier å spise fisk, og ber deg fylle ut spørsmålene om fiskeforbruk så godt du kan. Tilgangen på fisk kan variere gjennom året. Vær vennlig å markere i hvilke årstider du spiser de ulike fiskeslagene.

	aldri/ sjelden	like mye hele året	vinter	vår	sommer	høst
Torsk, sei, hyse, lyr	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steinbit, flyndre, uer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Laks, ørret	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Makrell	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sild	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annen fisk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Med tanke på de periodene av året der du spiser fisk, hvor ofte pleier du å spise følgende til middag?

(Sett ett kryss pr. linje)

	aldri/ sjelden	1 pr. mnd.	2-3 pr. mnd.	1 pr. uke	2+ pr. uke
Kokt torsk, sei, hyse, lyr	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stekt torsk, sei, hyse, lyr	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steinbit, flyndre, uer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Laks, ørret	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Makrell	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sild	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annen fisk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Dersom du spiser fisk, hvor mye spiser du vanligvis pr. gang? (1 skive/stykke = 150 gram)

Kokt fisk (skive)	<input type="checkbox"/>	1	<input type="checkbox"/>	1,5	<input type="checkbox"/>	2	<input type="checkbox"/>	3+
Stekt fisk (stykke)	<input type="checkbox"/>	1	<input type="checkbox"/>	1,5	<input type="checkbox"/>	2	<input type="checkbox"/>	3+

Hvor mange ganger pr. år spiser du fiskeinnmat?

(Sett ett kryss pr. linje)

	0	1-3	4-6	7-9	10+
Rogn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fiskelever	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Dersom du spiser fiskelever, hvor mange spise-skjeer pleier du å spise hver gang? (Sett ett kryss)

<input type="checkbox"/>	1	<input type="checkbox"/>	2	<input type="checkbox"/>	3-4	<input type="checkbox"/>	5-6	<input type="checkbox"/>	7+
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Hvor ofte bruker du følgende typer fiskemat?

(Sett ett kryss pr. linje)

	aldri/ sjelden	1 pr. mnd.	2-3 pr. mnd.	1 pr. uke	2+ pr. uke
Fiskekaker/pudding/boller	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Plukkfisk/fiskegrateng	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Frityrfisk/fiskepinner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor stor mengde pleier du vanligvis å spise av de ulike rettene? (Sett ett kryss for hver linje)

- Fiskekaker/pudding/boller (stk.) 1 2 3 4+
 (2 fiskeboller=1 fiskekake)
- Plukkfisk, fiskegrateng (dl) 1-2 3-4 5+
- Fritryfisk, fiskepinner (stk.) 1-2 3-4 5-6 7+

I tillegg til informasjon om fiskeforbruk er det viktig å få kartlagt hvilket tilbehør som blir servert til fisk. Hvor ofte bruker du følgende til fisk?

- | | aldri/sjelden | 1 pr. mnd. | 2-3 pr. mnd. | 1 pr. uke | 2+ pr. uke |
|----------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Smeltet/fast smør | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Smeltet/fast margarin/fett | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Seterrømme (35%) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Lettrømme (20%) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Saus med fett (hvit/brun) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Saus uten fett (hvit/brun) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

For de ulike typene tilbehør du bruker til fisk, vær vennlig å kryss av for hvor mye du vanligvis pleier å spise.

- | | | | | | |
|-----------------------------|------------------------------|------------------------------|------------------------------|----------------------------|-----------------------------|
| Smeltet/ fast smør (ss) | <input type="checkbox"/> 1/2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4+ |
| Smeltet/ fast margarin (ss) | <input type="checkbox"/> 1/2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4+ |
| Seterrømme (ss) | <input type="checkbox"/> 1/2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4+ |
| Lettrømme (ss) | <input type="checkbox"/> 1/2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4+ |
| Saus med fett (dl) | <input type="checkbox"/> 1/4 | <input type="checkbox"/> 1/2 | <input type="checkbox"/> 3/4 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2+ |
| Saus uten fett (dl) | <input type="checkbox"/> 1/4 | <input type="checkbox"/> 1/2 | <input type="checkbox"/> 3/4 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2+ |

Hvor ofte spiser du skalldyr (f. eks. reker, krabbe og skjell)? (Sett ett kryss)

- Aldri/sjelden 1 pr. mnd 2-3 pr. mnd 1+ pr. uke

Kjøtt

Hvor ofte spiser du reinkjøtt?

- Aldri/sjelden 1 pr. mnd. 2-3 pr. mnd. 1 pr. uke
 2-3 pr. uke 4+ pr. uke

Hvor ofte spiser du følgende kjøtt- og fjærkreretter?

- | (Sett ett kryss for hver rett) | aldri/sjelden | 1 pr.mnd. | 2-3 pr.mnd. | 1 pr.uke | 2+ pr.uke |
|--------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Steik (okse, svin, får) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Koteletter | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Biff | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Kjøttkaker, karbonader | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Pølser | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Gryterett, lapskaus | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Pizza med kjøtt | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Kylling | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Bacon, flesk | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Andre kjøttretter | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Dersom du spiser følgende retter, oppgi mengden du vanligvis spiser: (Sett ett kryss for hver linje)

- Steik (skiver) 1 2 3 4 5+
- Koteletter (stk.) 1/2 1 1,5 2+
- Kjøttkaker, karbonader (stk.) 1 2 3 4+
- Pølser (stk. à 150g) 1/2 1 1,5 2+
- Gryterett, lapskaus (dl) 1-2 3 4 5+
- Pizza m/kjøtt (stykke à 100 g) 1 2 3 4+

Hvilke sauser bruker du til kjøttretter og pastaretter?

- (Sett ett kryss pr. linje)
- | | aldri/sjelden | 1 pr. mnd. | 2-3 pr. mnd. | 1 pr. uke | 2+ pr. uke |
|----------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Brun saus | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Sjysaus | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Tomatsaus | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Saus med fløte/rømme | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Hvor mye bruker du vanligvis av disse sausene?

- Brun saus (dl) 1/4 1/2 3/4 1 2+
- Sjysaus (dl) 1/4 1/2 3/4 1 2+
- Tomatsaus (dl) 1/4 1/2 3/4 1 2+
- Saus med fløte/rømme (dl) 1/4 1/2 3/4 1 2+

Andre matvarer

Hvor mange egg spiser du vanligvis i løpet av en uke?(stekte, kokte, eggerøre, omelett) (Sett ett kryss)

- 0 1 2 3-4
 5-6 7+

Hvor ofte spiser du iskrem? (til dessert, Krone-is osv.) Sett ett kryss for hvor ofte du spiser iskrem om sommeren, og ett kryss for resten av året

- | | aldri/sjelden | 1 pr. mnd. | 2-3 pr. mnd. | 1 pr. uke | 2+ pr.uke |
|----------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Om sommeren | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Resten av året | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Hvor mye is spiser du vanligvis pr. gang? (Sett ett kryss)

- 1 dl 2 dl 3 dl 4+ dl

Hvor ofte spiser du bakevarer som boller, kaker, wienerbrød eller småkaker (Sett ett kryss pr. linje)

- | | aldri/sjelden | 1-3 pr. mnd. | 1 pr. uke | 2-3 pr. uke | 4-6 pr. uke | 1+ pr.dag |
|-------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Gjærbakst (boller o.l.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Wienerbrød, kringle | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Kaker | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Pannekaker | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Vafler | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Småkaker, kjeks | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Lefser, lomper | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Hvor ofte spiser du dessert? (Sett ett kryss pr. linje)

	aldri/ sjelden	1 pr. mnd.	2-3 pr. mnd.	1 pr. uke	2-3 pr. uke	4+ pr. uke
Puttering sjokolade/karamell	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Riskrem, fromasj	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kompott, fruktgrøt, hermetisk frukt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jordbær (friske, frosne)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Andre bær (friske, frosne)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor ofte spiser du sjokolade? (Sett ett kryss)

	aldri/ sjelden	1-3 pr. mnd.	1 pr. uke	2-3 pr. uke	4-6 pr. uke	1+ pr.dag
Mørk sjokolade	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lys sjokolade	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Dersom du spiser sjokolade, hvor mye pleier du vanligvis å spise hver gang? Tenk deg størrelsen på en

Kvikk-Lunsj sjokolade, og oppgi hvor mye du spiser i forhold til den.

1/4 1/2 3/4 1 1,5 2+

Hvor ofte spiser du snacks? (Sett ett kryss)

	aldri/ sjelden	1-3 pr. mnd.	1 pr. uke	2-3 pr. uke	4-6 pr. uke	1+ pr. dag
Potetchips	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Peanøtter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Andre nøtter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annen snacks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Tran og fiskeoljekapsler

Bruker du tran (flytende)? Ja Nei

Hvis ja; hvor ofte tar du tran?

Sett ett kryss for hver linje.

	aldri/ sjelden	1-3 pr. mnd.	1 pr. uke	2-6 pr. uke	daglig
Om vinteren	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Resten av året	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor mye tran pleier du å ta hver gang?

1 ts. 1/2 ss. 1+ ss.

Bruker du tranpiller/fiskeoljekapsler? Ja Nei

Hvis ja; hvor ofte tar du tranpiller/fiskeoljekapsler?

Sett ett kryss for hver linje.

	aldri/ sjelden	1-3 pr. mnd.	1 pr. uke	2-6 pr. uke	daglig
Om vinteren	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Resten av året	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvilken type tranpiller/fiskeoljekapsler bruker du vanligvis, og hvor mange pleier du å ta hver gang?

Antall

Navn _____

Kosttilskudd

Bruker du kosttilskudd? Ja Nei

Hvis ja, hvor ofte bruker du kosttilskudd?

(Sett ett kryss pr. linje)

Navn på kosttilskudd	aldri/ sjelden	1-3 pr. mnd.	1 pr. uke	2-6 pr. uke	daglig
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Bruker du soyapreparater mot plager i overgangsalderen? Ja Nei

Varm mat

Hvor mange ganger i løpet av en måned spiser du varm mat?

Til frokost Til middag
Til lunsj Til kvelds

Kosthold som barn

Hvor mye melk drakk du som barn hver dag? (sett ett kryss)

drakk ikke melk 1-3 glass 4-6 glass 7 glass eller mer

Hvor ofte spiste du grønnsaker til middag som barn?

(sett ett kryss)

aldri 1 gang i uken eller mer sjelden
 2-3 ganger i uken 4 eller flere ganger pr. uke

Hvor ofte spiste du fisk til middag som barn? (sett ett kryss)

aldri 1 gang i uken eller mer sjelden
 2-3 ganger i uken 4 eller flere ganger pr. uke

Alkohol

Er du totalavholdskvinne? Ja Nei

Hvis Nei; hvor ofte og hvor mye drakk du i gjennomsnitt siste året? (Sett ett kryss for hver linje)

	aldri/ sjelden	1 pr. mnd.	2-3 pr. mnd.	1 pr. uke	2-4 pr. uke	5-6 pr. uke	1 pr. dag	2+ pr. dag
Øl (1/2 l.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vin (glass)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brennevin (drink)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Likør/Hetvin (glass)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Sosiale forhold

Er du idag: (Sett ett kryss)

gift samboer ugift skilt enke

Hvor mange personer er det i ditt hushold?

Hvor høy er bruttoinntekten i husholdet pr. år?

inntil 150.000 kr. 151.000-300.000 kr.
 301.000-450.000 kr. 451.000-600.000 kr.
 601.000-750.000 kr. over 750.000 kr.

Hva er din arbeidssituasjon? (sett ett eller flere kryss)

Arbeider heltid Arbeider deltid Pensjonist
 Hjemmearbeidende Under utdanning Uføretrygdet
 Under attføring Arbeidssøkende

Arbeider du utendørs i yrkessammenheng? Ja Nei

Hvis Ja; hvor mange timer pr. uke? Sommer Vinter

Solvaner

Får du fregner når du soler deg? Ja Nei

For å kunne studere effekten av soling på risiko for hudkreft, ber vi deg gi opplysninger om hudfarge. Sett ett kryss på det tallet under fargen som best passer din naturlige hudfarge (uten soling).

1	2	3	4	5	6	7	8	9	10

Hvor mange ganger pr. år er du blitt forbrent av solen slik at du har fått svie eller blemmer med avflassing etterpå? (ett kryss for hver aldersgruppe)

Alder	Aldri	Høyst 1 gang pr. år	2-3 g. pr. år	4-5 g. pr. år	6 eller flere ganger pr. år
40-49 år	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50 + år	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor mange uker i gjennomsnitt pr. år har du vært på badeferie i syden eller i Norge?

Alder	Aldri	1 uke	2-3 uker	4-5 uker	7 uker eller mer
40-49 år	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50 + år	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Siste 12 mnd.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor ofte har du solt deg i solarium?

Alder	Aldri	Sjelden	1 gang pr. mnd.	2 ganger pr. mnd.	3-4 ganger pr. mnd.	oftere enn 1 gang pr. uke
40-49 år	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50+ år	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Siste 12 mnd.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor ofte dusjer eller bader du?

	mer enn 1 g. dagl.	1 g. dagl.	4-6 g. pr. uke	2-3 g. pr. uke	1 g. pr. uke	2-3 g. pr. mnd.	sjelden/aldri
Med såpe/shampo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uten såpe/shampo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Når bruker du krem med solfaktor? (sett evt. flere kryss):

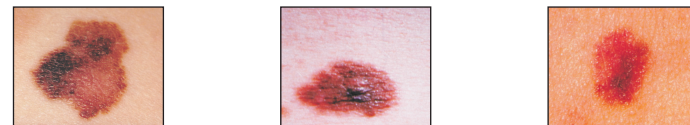
i påsken i Norge eller utenfor syden
 solferie i syden aldri

Hvilken solfaktor bruker du i disse periodene?

	Ingen	1-4	5-9	10-14	15+
Påsken	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I Norge eller utenfor syden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Solferie i syden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor mange uregelmessige føflekker større enn 5 mm har du sammenlagt på begge beina (fra tærne til lysken)? Tre eksempler på føflekker større enn 5 mm med uregelmessig form er vist nedenfor.

0 1 2-3 4-6 7-12 13-24 25+



5 mm

Hvor ofte bruker du følgende hudpleiemidler?

(Sett ett kryss pr. linje)

	aldri/sjelden	1-3 pr.mnd.	1 pr.uke	2-4 pr.uke	5-6 pr.uke	1 pr.dag	2+ pr. dag
Ansiktskrem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Håndkrem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Body lotion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parfyme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Til slutt vil vi spørre deg om ditt samtykke til å kontakte deg på nytt pr. post. Vi vil hente adressen fra det sentrale personregister.

Ja Nei

Er du villig til å avgi en blodprøve?

Ja Nei

Takk for at du ville delta i undersøkelsen

Forespørsel om deltakelse i forskningsprosjektet

The work of handling self-reported food hypersensitivity

Arbeidet med å handtere selvrapportert matoverfølsomhet

Bakgrunn og formål

Antallet personer som har matoverfølsomhet (matallergi eller matintoleranse) ser ut til å være økende, og vi ønsker å gjennomføre et forskningsprosjekt der vi ser nærmere på denne gruppen.

Formålet med prosjektet er å kunne bidra med kunnskap som kan forbedre situasjonen for personer med matallergi og matintoleranse.

Forskningsprosjektet består av to deler: I den første delen vil vi kartlegge omfanget av selvrapportert matoverfølsomhet og hva som kjennetegner denne gruppen. I den andre delen vil vi kartlegge hvilke erfaringer personer med matoverfølsomhet har med å leve med og håndtere matoverfølsomheten.

Du er invitert til å delta på den andre delen, det vil si at vi ønsker å intervju deg om dine erfaringer med å ha matoverfølsomhet. I intervjuene kommer vi til å legge vekt på hvordan du fant ut at du ikke tåler enkelte matvarer, hva du gjør i hverdagen for å håndtere dette og hvordan andre personer forholder seg til dette.

Dette forskningsprosjektet er et doktorgradsprosjekt som er finansiert av og gjennomføres ved Institutt for samfunnsmedisin, UiT Norges arktiske universitet.

De 16-20 personene som vil bli spurt om å ta del i del i intervjuene, er personer som selv oppfatter at de har matoverfølsomhet, og disse personene er eller vil bli rekruttert via Astma- og allergiforbundet, Norsk Cøliakiforening og via snøballmetoden.

Hva innebærer deltakelse i studien?

Deltakelse i studien innebærer at du deltar på et intervju med varighet på ca. 1 -2 timer, og intervjuet vil bli tatt opp og skrevet ut ordrett (transkribert). Du kan selv bestemme hvor du ønsker å gjennomføre intervjuet.

Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Kort tid etter intervjuet vil lydopptaket bli overført fra lydopptakeren til Tjeneste for Sensitive data (TSD). Dette er en plattform som oppfyller de strenge kravene til oppbevaring av intervjudata. For mer informasjon om TSD se <http://www.uio.no/tjenester/it/forskning/sensitiv/>.

Så snart lydopptaket er overført til TSD, vil det bli slettet fra lydopptakeren, og lydopptakeren oppbevares i låst skap. Listen med navn og kontaktopplysninger vil bli oppbevart adskilt fra øvrige data. Kun stipendiat Monika Dybdahl Jakobsen, forskningsleder Birgit Abelsen, professor Aud

Obstfelder og førsteamanuensis Tonje Braaten vil ha tilgang på lydopptaket, det transkriberte intervjuet og navnelisten.

Når forskningen publiseres, vil ingen deltakere kunne gjenkjennes.

Prosjektet skal etter planen avsluttes 31.12.2017, og da vil lydopptak og navneliste bli slettet. Anonyme transkriberte intervjuer oppbevares av Tjeneste for Sensitive data i fem år etter prosjektslutt.

Frivillig deltakelse

Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert.

Dersom du ønsker å delta eller har spørsmål til studien, ta kontakt med stipendiat Monika Dybdahl Jakobsen tlf. 99505829 eller forskningsleder Birgit Abelsen tlf. 95870987.

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta i intervju

(Signert av prosjektdeltaker, dato)

Appendix 4

Tema under intervjuet:

Kunnskap

Hvordan fikk du kunnskap om matoverfølsomheten og hvordan denne kunne håndteres. Hvordan du fant ut at du hadde matoverfølsomhet?

Konkrete tiltak

Hva gjør du i hverdagen for å handtere matoverfølsomheten?

Andre personer

Hvordan forholder andre personer seg til matoverfølsomheten din, og hva må du gjøre i forhold til andre eller si til andre for blant annet å unngå at de gir deg mat du ikke tåler?

Endring/evaluering

Har du endret måten du håndterer matoverfølsomheten på?

Appendix 5

Veldig hyggelig at vil delta.

Si litt om prosjektet. Todelt, og at den siste og største delen handler om hvordan det er å håndtere matoverfølsomhet altså matallergi eller –intoleranse. At jeg tror diagnose og andre sykdommer vil kunne spille inn.

Jeg er ute etter dine erfaringer og de bare må snakke i vei, samtidig er helt OK å ikke svare på ting en ikke vil svare på etc.

Se på informasjonsskrivet (igjen), og jeg spør om de har spørsmål. Signere.

1. Hva gjort for å forstå MO og hvordan den håndteres

Å forstå matoverfølsomheten

Hvilke symptomer som skyldes hva. Hvilke undersøkelser de bør gjøre og resultatet av disse.
Hva de kan spise og ikke spise.
Hva slags konsekvenser dietten kan ha.
Helsepersonells roller.

Å skaffe seg informasjon om MO og hvordan de bør håndtere den ved hjelp av andre.
Å skaffe seg info/forståelse selv.
Om de opplever at deres erfaringer er i tråd med informasjonen de har fått.

Har de et tydelig bilde av MO?
Vet de om og når de bør søke hjelp?

Fortell om hvordan du fant ut at du ikke tåler.. (de matvarene hun har sagt hun ikke tåler)

Hvilke (medisinske?) undersøkelser har du gjort, hvordan fant du ut hva disse betydde, hvordan fant du ut at du skulle gjøre disse undersøkelsene?

Hvordan fant du ut hva du kan spise? (Helt konkret når er på butikken/skal lage et måltid.)

Har du fått hjelp av andre (helsepersonell/alternativ medisiner) til å finne ut av din matoverfølsomhet? hvilke, hva har du fått hjelp av dem til, hvordan fant du ut at de kunne hjelpe deg?

Hvordan fikk du informasjon om sykdommen? Fikk du info fra andre, hvilken info da, fra hvem?

Har du funnet ut om MO selv, hva, hvordan?

I hvilken grad opplever du at det er samsvar mellom det du har fått vite fra andre kilder og det du selv opplever/har opplevd?

Føler du at du har fått oversikt over din egen tilstand? (For eksempel om det det er på tide å søke hjelp?)

2. Hva gjør av konkrete ting i hverdagen

Hva gjør du konkret i hverdagen for ivareta MO/holde deg friskest mulig?

Hva de **konkret gjør** i hverdagen for å ivareta MO, og hva de gjør ved forverring.

Hva gjør dere når dere spiser hjemme? Fortell om hvordan lager middag (vanlig/typisk).
Hva gjør du når du spiser ute? Skal på ferie?
Hva gjør du i forhold til matinnkjøp? Fortell om hvordan handler (vanlig/typisk).

Hvilke **rutiner** de har laget (ifht handling, matlaging, når de skal ut).

Hva gjør du hvis du blir dårlig/ har fått i deg noe du ikke tåler?

Hvordan er dette nå sammenlignet med før?

Hvilke **ressurser** har de ivaretatt /ordnet seg? (Økonomisk og sosialt).

Får du økonomisk støtte? Hvordan fikk du i tilfelle dette?

3. Samhandlingen med andre

Man spiser jo ofte sammen med andre, hva gjør du da for å unngå å få i deg...?

Å **informere andre** om hva de kan spise og ikke spise og hvordan dette løses.

Hva sier du til andre (hvilken informasjon gir du andre) sånn at de kan servere deg mat du tåler?

Har søkt **bekreftelse hos andre**, og hvordan var det?

Hvordan reagerer andre når du sier det er mat du ikke kan spise?

4. Evaluering/endring

Neste tema handler om endring. Du har jo funnet måter å handtere MO. Har du måttet endre på dette underveis?

Om de må **endre rutiner**, og mer om dette arbeidet.
Om arbeidet med å evaluere rutiner i **samarbeid med andre**.

Du sa at du gjør.....for å unngå å få i deg..., har det det alltid vært slik? Har du noen gang endra på opplegget underveis?
Diskuterer du opplegget/måten du håndterer din MO med andre? Hvem, hva er det dere snakker om?

Om det arbeidet med å evaluere rutiner som de gjør selv.

Har du endra opplegget selv, hva, hvordan, hvorfor?

Om det er noe de holder seg **oppdatert** på.

Hender det at det skjer noe nytt, ja noe du følger med på for å ivareta din MO? (Oppskrifter for eksempel)

Annet

Er dette noe du rekker å gjøre? *(Hva er det som gjør at dette fungerer, at de får gjort arbeidet?)*

Jobb med andre sykdommer?/Hva må gjøre i forhold til de andre sykdommene

Hatt/Har kontakt med helsetjeneste (evt. hvilken)? Ville du ønsket mer hjelp fra helsetjeneste (evt. hvilken?)

Familie, barn, jobb?

Er det noe mer du gjerne vil vi skal snakke om?

Høgeste fullførte utd. (grskole, vid, bachelor, mer?)

Tusen takk

Appendix 6

Odds ratios (OR) with p values of self-reported food hypersensitivity by comorbidities* in the Norwegian Women and Cancer study. Imputed data. Also the depression and hypothyroid variables are imputed.

Comorbidities	OR**	p
No comorbidities (ref.)	1.00	
Muscle pain (myalgia) only	1.79	<0.001
Fibromyalgia/fibrositis only	1.75	0.001
Back pain only	1.25	0.003
Depression only	1.26	0.001
Hypothyroidism only	1.56	<0.001
Chronic fatigue only	2.16	<0.001
2 concurrent comorbidities	2.10	<0.001
3 concurrent comorbidities	2.93	<0.001
4 concurrent comorbidities	4.03	<0.001
5–6 concurrent comorbidities	5.25	<0.001

* The six comorbidities considered were muscle pain (myalgia), fibromyalgia/fibrositis, back pain, depression, hypothyroidism and chronic fatigue.

**Adjusted for age, place of residence, duration of education, employment status, economic conditions in childhood, partner status, alcohol consumption, smoking status, and body mass index.

Missing values

Supplementary table A. Distribution of missing values for the variables included in the logistic regression analyses.

Variable	Missing values
Self-reported food hypersensitivity	0 ¹
Age	0
Place of residence	0
Education	3,425
Employment status	618
Economic conditions in childhood	3,997
Partner status	312
Smoking status	1,841
Alcohol consumption (g/day)	3,123
BMI	2,639
Self-perceived health	2905
Muscle pain (myalgia)	0 ¹
Fibromyalgia/fibrositis	0 ¹
Back pain	0 ¹
Depression	12,391
Hypothyroidism	15,957
Chronic fatigue	0 ¹

¹Women who ticked off for having the condition were interpreted as reporting the health complaint, and the rest as not reporting the health complaint.

Logistic regression based on complete case data

Supplementary table B. Odds ratios (OR) with p values of self-reported food hypersensitivity by participant characteristics, the Norwegian Women and Cancer study (complete case data).

	OR	p
Age (years)	0.97	<0.001
Place of residence		
Not central (ref.)	1.00	
Central	1.11	0.004
Duration of education (years)		
≤9 (ref.)	1.00	
10-12	1.30	<0.001
13-16	1.43	<0.001
≥17	1.69	<0.001
Employment status		
Full-time work (ref.)	1.00	
Not full-time work	1.28	<0.001
Economic conditions in childhood		
Good (ref.)	1.00	
Poor	1.18	<0.001
Partner status		
Living with partner (ref.)	1.00	
Not living with partner	1.27	<0.001
Smoking status among non-alcohol consumers		

Never (ref.)	1.00	
Former	1.39	<0.001
Current	0.87	0.224
Smoking status among alcohol consumers (≥ 0.1 g/day)		
Never (ref.)	1.00	
Former	0.92	0.029
Current	0.79	<0.001
Body mass index (kg/m ²)		
<20	1.42	<0.001
20-24.9 (ref.)	1.00	
≥ 25	0.99	0.859
Self-perceived health		
Good (ref.)	1.00	
Poor	2.57	<0.001

Supplementary table C. Odds ratios (OR) with p values of self-reported food hypersensitivity by comorbidity in the Norwegian Women and Cancer study (complete case data).

Comorbidities	OR¹	p
No comorbidities (ref.)	1.00	
Muscle pain (myalgia) only	1.77	<0.001

Fibromyalgia/fibrositis only	1.80	0.001
Back pain only	1.22	0.009
Depression only	1.27	0.001
Hypothyroidism only	1.57	<0.001
Chronic fatigue only	2.32	<0.001
2 concurrent comorbidities	2.05	<0.001
3 concurrent comorbidities	2.93	<0.001
4 concurrent comorbidities	4.18	<0.001
5-6 concurrent comorbidities	4.75	<0.001

¹Adjusted for age, place of residence, duration of education, employment status, economic conditions in childhood, partner status, alcohol consumption, smoking status, and body mass index.