

Is it the gluten-free diet that matters the most?

Food, gender, and celiac disease

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Dedicated to Michael, Erica, Fredrik, and Per

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Abstract

Background

The only treatment for celiac disease consists of excluding gluten. Gluten is a protein complex found in wheat, rye, and barley, which are cereals commonly used in bread, pasta, pizza, etc. The overall aims of this thesis were to study; what happens with food choices and nutrient intakes when individuals are prescribed a gluten-free diet and what consequences this has on the everyday lives of young women and young men dealing with this disease.

Methods

A food frequency questionnaire (FFQ) was used to study nutrient intake and how food choices were affected after a change to a gluten-free diet. The FFQ was sent to 12-13 years-old adolescents who took part in a large Swedish celiac screening study. The following three groups were studied: previously diagnosed with celiac disease, screening-diagnosed and non-celiac controls. The first FFQ was sent out before the screening-diagnosed adolescents had been told they had celiac disease, and the second was sent 12-18 months after they had been prescribed the gluten-free treatment. Semi-structured interviews were performed five years later in order to study how everyday life was affected by celiac disease in seven young women and seven young men. The interviews were analyzed by content analysis.

Results

The previously diagnosed celiac disease group reported a nutrient intake in line with the non-celiac control group. Most of the participants reported a nutrient intake above the estimated average requirements. A diagnosis of celiac disease altered the intake of some foods, and this was shown by comparing the results from the baseline FFQ before the diagnosis and the follow-up FFQ after. The young women and men reported similar experiences of the gluten-free food, but the perceived consequences of living with celiac disease differed between genders.

Conclusion

This thesis shows that after a diagnosis of celiac disease food changes are necessary in order to be compliant with the gluten-free diet. One common effect is that food options will be reduced. However, as long the food intake is

gluten-free, varied, and in sufficient quantity there is no reason to worry more about the nutritional intake of adolescents diagnosed with celiac disease than there is for their non-celiac peers. The findings in this thesis also show that the society's gender order has a great impact on how young women and young men experience their everyday lives, with celiac disease, and with the gluten-free diet.

Abbreviations

BMI	Body Mass Index
BMR	Basal Metabolic Rate
CD	Celiac Disease
DLW	Double Label Water
EAR	Estimated Average Requirements
E%	Percentage of energy from macronutrient, in relation to total energy intake
EI	Energy intake
ETICS	Exploring the Iceberg of Celiacs in Sweden
FFQ	Food frequency questionnaire
FIL	Food Intake Level
NNR	Nordic Nutrition Recommendation
PAL	Physical Activity Level
QoL	Quality of Life
SD	Standard Deviation

Populärvetenskaplig Svensk sammanfattning

Bakgrund

Vardagslivet är kantat av allmänna normer som berättar hur vi ska vara och uppträda. Normerna behöver inte uttalas, de finns där, och vi fostras in i dem, ofta utan att reflektera över att normerna är konstruerade regler i vårt samhälle. Normerna berättar hur saker och ting har varit, och om de inte förändras, berättar de också hur vi förväntas uppträda för att passa in.

Det finns både biologiska och konstruerade skillnader mellan kvinnor och män, men de biologiska likheterna är fler än skillnaderna. De socialt konstruerade skillnaderna mellan kvinnor och män är många, dessa ses ibland som eftersträvensvärda; de vackra, smala kvinnorna och barnen blir räddade först vid en katastrof, mannen blir hjälte, maskulin och stark – i alla fall uttrycks ofta den bilden på kvinnor och män på bioduken. Verkligheten är blekare men strävan efter idealen påverkar oss ofta i många situationer i vardagen. Nackdelarna med att efterleva samhällets könsnormer är bland annat att fastlåsta stereotypa beteenden verkar hämmande. Det kan bli svårt för kvinnor och män att leva upp till samhällets konstruerade idealbild på hur kvinnor och män förväntas vara och bete sig. Det kan också ifrågasättas om det är eftersträvensvärt, och vem som vinner eller förlorar mest i ett sådant perspektiv.

Oavsett vem du är och var du kommer ifrån behöver din kropp näring och energi för att kunna fungera. Näring och energi får vi genom maten. Men mat är mycket mer än bara näringsämnen. Maten som vi föredrar och tycker om är ingen tillfällighet, preferenser gällande mat har utvecklats från tidigare åldrar och erfarenheter, ekonomiska möjligheter osv. i en specifik kultur. Vid umgänget kring mat och måltider kommer det sociala samspelet att påverka valet av mat och mängd. Mat används ofta som en symbol för att uttrycka känslor och värderingar.

Det finns samband mellan matval och hälsa. Ett tydligt exempel är den kroniska sjukdomen celiaki och mat. Celiaki är en auto-inflammatorisk sjukdom som via inflammation i tarmslemhinnan leder till att tarmluddet minskar, vilket medför att ytan för näringsupptag i tarmen minskar. När en individ får diagnosen celiaki rekommenderas individen att påbörja den enda fungerande behandling, att utesluta gluten ur kosten. Gluten är ett proteinkomplex som finns i vete, korn och råg. Dessa spannmål är vanligt

förekommande i vår svenska mathållning, i till exempel bröd, pasta, bakverk etc.

Celiaki är en av de vanligaste kostrelaterade sjukdomarna som drabbar barn och ungdomar. Sverige har den högsta förekomsten av celiaki hos barn (ca 3 %) i väst världen. Prevalensen som har celiaki i Europa är ca 1 %. Det är fler flickor/kvinnor som diagnosticeras och utvecklar sjukdomen jämfört med pojkar/män (3:1). Vid studier om celiaki brukar de barn som har symtom och blir diagnosticerade inom sjukvården ofta benämnas symtom upptäckta. Vissa som har sjukdomen har dock otydliga eller inga symtom trots att de har sjukdomen. Sjukdomen kan utvecklas hos både barn och vuxna och diagnosticeras via ett blodprov som visar om det finns förhöjda serologiska markörer för celiaki. Förhöjda serologiska markörer indikerar att det bildas antikroppar mot gluten och en tarmbiopsi görs. Utifall att provet från tunntarmen visar att vecken (villi), som normalt ska finnas i tunntarmen, är påverkade eller saknas helt kan diagnosen fastställas.

Syftet med denna avhandling var, dels att undersöka näringsintaget i en glutenfri kost och studera hur maten påverkas när en individ blir ordinerad en glutenfri kost. Syftet var även att belysa konsekvenser i vardagen hos unga kvinnor och unga män efter att de blivit diagnosticerade med sjukdomen celiaki.

Metoder

Näringsintaget i en glutenfri kost samt hur maten påverkades av en diagnos av celiaki studerades med hjälp av matfrekvensformulär designat för ungdomar i 6:e klass och dess föräldrar. Barnen deltog i en stor (totalt var 10 041 ungdomar inbjudna) svensk studie där ungdomarna screenades för celiaki, Exploring the Iceberg of Celiacs in Sweden, ETICS. Första utskicket av matfrekvensformuläret gjordes efter att ungdomarna hade lämnat blodprov för screeningen, och ett andra utskick av matfrekvensformuläret skedde 12-18 månader senare. Matfrekvensformuläret innehöll frågor om hur stor mängd och hur ofta ungdomen ätit av 57 olika livsmedel under de senaste fyra veckorna. Vid första utskicket av matfrekvensformuläret, rapporterade de, som sedan kom att bli screenade till diagnosen celiaki sitt matintag som de åt innan de fick diagnosen. I det andra matfrekvensformuläret rapporterade de screeningupptäckta ungdomarna sitt matintag och hur ofta de valde att äta glutenfritt. Denna studiedesign innebar att förändringar av matintaget efter en diagnos av celiaki kunde studeras. Två jämnåriga kontrollgrupper deltog; varav en grupp bestod av ungdomar med symtomupptäckt celiaki som diagnosticerats i tidig ålder och den andra av ungdomar utan celiaki. För att belysa konsekvenser i vardagen för unga kvinnor och unga män, 5 år efter att

de diagnosticerats med sjukdomen celiaki, genomfördes totalt 14 intervjuer, 7 med unga kvinnor och 7 med unga män. Intervjuerna analyserades med hjälp av innehållsanalys enligt Graneheim & Lundman.

Resultat och slutsatser

Näringsintaget hos ungdomarna som åt en glutenfri kost var jämförbart med näringsintaget för kontrollgruppen utan celiaki. Emellertid visade studien att det fanns ett behov för samtliga grupper att förbättra sitt intag av fibrer och minska intaget av mättade fetter. Matintaget förändrades för de ungdomar som via screeningen diagnostiserades till celiaki när de blivit ordinerade en glutenfri kost. De bytte de vanliga gluteninnehållande produkterna, bröd och pasta, till glutenfria ersättningsprodukter. De screeningupptäckta ungdomarna minskade sitt intag av fikabröd, pizza och chicken nuggets och intaget av charkprodukter ökade.

Analysen av intervjuerna visade att de unga kvinnorna och de unga männen hade liknande upplevelser och erfarenheter av de glutenfria produkterna. De beskrev att först hade de upplevt smaken på de glutenfria produkterna som äcklig, men eftersom att de ansåg att de inte hade haft annat något val än att acceptera smaken, innebar det att de vande sig vid den nya smaken. Vid tiden för intervjuerna menade de att glutenfria produkter var goda, om de var väl tillagade. Däremot visade analysen att erfarenheter av hur kostbehandlingen påverkade vardagen skilde sig åt mellan de unga kvinnorna och de unga männen.

De unga kvinnorna berättade att de upplevde sjukdomen som begränsande, de beskrev att de kände ett stort ansvar både för sin egen hälsa i relation till mat och för hur andra upplevde deras behov av glutenfri kost. Samhällets normer på hur kvinnlighet; såsom att vissa empati och förståelse för andra, inte ta plats, och ställa krav på sin omgivning tolkades som hinder de unga kvinnorna fick brottas med för att följa en strikt glutenfri kost.

I samband med att de unga männen fick beskedet att de hade celiaki och påbörjade den glutenfria kostbehandlingen upplevde en del att deras fysiska hälsa tydligt förbättrades. Negativa erfarenheter i samband med diagnosen var även beskrivna av de unga männen, vilket resulterade i ökad stress i samband med att de blev medvetna om att de hade en kronisk sjukdom. Det blev tydligt i analysen att, i relation till vilken position den unga mannen hade i sin informella kamrat grupp, kunde de ställa olika krav på tillgänglighet av glutenfria produkter, och att dessa skulle smaka bra. Samhällets förväntningar på manlighet, som att uppträda självsäkert och ställa krav på sin omgivning, tolkades som förenligt med att följa en strikt glutenfri kost.

List of original papers

- I. Kautto E, Ivarsson A, Norström F, Högberg L, Carlsson A, Hörnell A. Nutrient intake in adolescent girls and boys diagnosed with coeliac disease at an early age is mostly comparable to their non-coeliac contemporaries. *Journal of Human Nutrition and Dietetics*, May, 2013. (Published)
- II. Kautto E, Rydén PJ, Ivarsson A, Olsson C, Norström F, Högberg L, Carlsson A, Hagfors L, Hörnell A. What happens to food choices when a gluten-free diet is required? A prospective longitudinal population based study among Swedish adolescent with celiac disease and their peers. *Journal Nutritional Science*. vol.3, 2014, (Published).
- III. Kautto E, Olsson C, Ivarsson A, Hörnell A, Aléx L. An on-going gendered endeavor in silence: young women struggling with celiac disease. Manuscript.
- IV. Kautto E, Olsson C, Ivarsson A, Hörnell A, Aléx L. Living with celiac disease, seen from a male perspective. Manuscript.

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Background

There are many studies about food related issues, celiac disease, and gender in the scientific literature. However, few studies, unite these subjects.

Following a diet

Eating is a universal experience that can be shared with other people around the globe because food is a component of every individual life. Health, culture, knowledge, economics, availability, and traditions are examples of major factors that determine the types of food consumed (1). From a nutritional perspective, the body needs a certain amount of nutrients to function properly regardless of those factors. Age, sex, body composition, physical activity, and food intake are important variables to consider when nutrients are being studied in relation to a healthy physical body (2). In Sweden, where there is normally plenty of food available, few healthy individuals experience any nutritional deficiencies. However, the intake of some nutrients such as poly-unsaturated fatty acids, vitamin D, and folate might be too low for a large proportion of the general population in Sweden (3, 4).

Ensuring sufficient nutrients in the diet is not the only priority that Swedish people might have today when deciding how to eat. It has become very common to eat according to various popular diets, which might include or exclude certain nutrients. One can voluntarily choose from a variety of diets to fulfill the personal goals. The reason for dietary change can differ among individuals even if the goal is similar, such as losing weight. For some, the reason is to be able to be more physical active, whereas others might want to lose weight before a sporting competition (5, 6). Another example is the choice of a vegetarian life-style, which can be due to concerns about one's own health or concerns about animal abuses and the environment (7). When having problems with the stomach, it is common to try to avoid certain foods or food components, such as lactose. If the problem disappears one can choose to deliberately avoid that food in the future (8).

A medical health-care professional might prescribe a dietary treatment if food intake needs to be changed to maintain or improve health regardless of the patient's personal choice. A patient with diabetes will probably be prescribed regular meal times, a low intake of rapidly metabolized carbohydrates, and a rich intake of fiber (9). A patient with head or neck cancer might have different dietary needs, such as texture adapted food, because of the location of the tumor or the effects of the cancer treatment (10). These examples of dietary

treatments suggest restrictions that could have implications on the diet and social meals.

Another type of dietary treatment is prescribed after a diagnosis with celiac disease: the gluten-free diet. This is a lifelong treatment in which gluten, a protein fraction found in wheat, rye, and barley, should be completely absent from the diet for the rest of the patient's life (11). A difference between the strict gluten-free treatment and the dietary treatments described above is that the gluten-free diet promises the advantage of being as healthy as any other as long as the dietary rules are followed.

A life-long disease

Celiac disease is an immunological inflammatory disease diagnosed by the presence of celiac-specific serological markers and the occurrence of villous atrophy in the upper small intestine, which is revealed by a biopsy (11). The function of the intestinal villi is the absorption of energy-providing compounds and nutrients. When the mucosal lining becomes flat or partially flat, the area available for absorbing nutrients is significantly reduced (11, 12). Usually this affects the first part of the intestine in an untreated celiac disease patient, which is an important area for the absorption of fat, fat-soluble vitamins, and other micronutrients such as iron and calcium (13). Therefore, the risk of having nutrient deficiencies is increased in celiac patients. When gluten is excluded from the diet, the villi and the absorption surface, are restored as long as the food continues to be gluten-free.

Several countries have reported an increase in the number of individuals diagnosed with celiac disease (14-17). The prevalence in Europe is about 1%, but among Swedish children, the prevalence is about 2.5%-3%, which is the highest reported rate in the Westernized world (17). For unknown reasons, more females than males are being diagnosed to celiac disease (11, 18). Celiac disease has come to be seen as a public health issue (19). Today an increased awareness of the disease and development of testing tools has contributed to making it easier to diagnose celiac disease (16, 20-22). Today, symptoms and signs are known to be diverse and could differ with age and from one individual to another, and some patients can even be asymptomatic (23). Examples of typical symptoms in untreated children are gastrointestinal problems and failure to thrive (11). In untreated adolescents and adults, symptoms include gastrointestinal problems, anemia, depression, fatigue, infertility, and osteoporosis (16, 24-26). Whether symptoms are present or not, the nutritional status of individuals with untreated celiac disease is

affected and depends on how long they have had the disease and the condition of the villi in the mucosa lining of the intestine (13).

The gluten-free food is the medicine

The dietary treatment for celiac disease is effective. The symptoms related to celiac disease in an untreated individual will disappear after adherence to a strict gluten-free diet (27). A turn to the gluten-free diet is often a noticeable change for the patient with celiac disease, even if the extent of the change depends on previous food habits. Bread, pastries, pasta, and pizza are examples of common food products that usually contain gluten and must be abandoned in their gluten-containing forms after a diagnosis with celiac disease. Instead non-gluten alternatives must be chosen. There are natural gluten-free alternatives such as rice, potatoes, buckwheat, and tapioca, and there are several manufactured gluten-free counterparts to ordinary bread, pastries, pasta, pizza, and so on. The gluten-free diet has been studied from a nutrient perspective and has often been described as high in saturated fat, protein and sugar, and low in fiber, calcium, folate, vitamin B12, iron, magnesium, and vitamin D (28-33).

In addition, a secondary lactose deficiency could occur if the celiac patient is left untreated, because the lactase enzyme is localized on the villi (12). This kind of secondary lactose deficiency is reversed after recovery with a gluten-free diet.

Power relations in health-care

A chronic medical diagnosis such as celiac disease means that the individual is incorporated into the dominant medical health-care system. Foucault (34), a French philosopher, stated that the medical system has a great influence on deciding what is considered normal and correct. He said in an interview in 1976, "Medical power is at the heart of the society of normalization", which indirectly implies that health-care holds a great deal of power (35). Foucault also wrote about the *clinical gaze*, which he described as the power the medical system holds through surveillance and monitoring (34). According to Holmes and Gastaldos, Foucault described power as something that could be both repressive and productive, both fluid and not one-sided (36). Foucault described power as always present, in all relations and in every society. An example is prescribed treatments that require that the patient take self-monitored actions, the treatment will affect the patient's behavior, and can be seen as ethical and moral governing. On the other side, the patient can ignore

the treatment. This thesis uses Holmes and Gastaldos interpretation of Foucault's term *governmentality*, which describes, in this case, how health-care governs the patient (36).

According to Holmes and Gastaldos, the health-care system governs by a subtle form of power to make a patient willing to act in the way that the health-care system has decided is the best way (36), and the patient is expected to use his or her own abilities to behave correctly. The power works in many different ways such as by hierarchical observation (the way in which patients are identified), defining what is normal, using the right to rebuke and reward the patient, and monitoring the patient through examination. In order to govern the patient, the health-care system also scrutinizes the patient's own consciousness (36). When the patient starts to use health-care as platform for confession, the health-care system obtains knowledge about the patient which is an essential part in enabling the use of its power. The knowledge obtained can then be transformed and used to control and direct the patient. When the patient meets the health-care staff and is encouraged to reflect upon and describe his or her situation, the patient becomes aware of his or her situation in terms of values of the health-care system. The patients then hopefully starts to change his or hers behavior in a favorable way.

Governing dietary treatment

When an individual is diagnosed with celiac disease, the patient is offered contacts with a physician and a dietitian who provides information about the disease as a whole and about the specific treatment. In Sweden, the Society for Pediatric Gastroenterology has published guidelines for how children with celiac disease should be monitored by health-care providers (37). The treatment is about self-governing; the patient must take care of his or her own treatment. Living with celiac disease has several practical implications. It means, for example, eating different foods, having fewer food options, and being forced to read labels when shopping for groceries (38). Reading labels is a time-consuming task and requires a reliable content declaration on the label (39). Following the diet leads to increased costs because specially manufactured gluten-free products are more expensive. Therefore, the Swedish government contributes economically to children and adolescents up to sixteen years of age who have been diagnosed with celiac disease. The financial contribution is paid by government taxes, and gluten-free products provided through pharmacies.

New cooking skills must also be learned. The gluten in ordinary flour is what gives the dough its elasticity and viscous properties when baking bread. It holds the gas and hopefully produces a fluffy bread with a nice color, which is

seen as important in Western society (40). When baking bread with gluten-free flour, however, the risk is increased of producing bread that is very pale with different texture because the characteristics of the flour is drastically different. Therefore, practice, knowledge, and use of sour-dough can improve the result when baking gluten-free bread (40).

Being able to restore health by just changing one's diet can from the outside, be seen as rather simple. However, the experience of being compliant to the gluten-free diet seems to vary significantly between individuals, and changing to a gluten-free diet has been known to be troublesome for many (41). Specific personal characteristics such as being committed, having self-control, and being responsible are known to be helpful in complying with the diet (42).

Gender in relation to health and food

A biological body and a socially constructed gender

In our society, we are surrounded by different norms that direct how we should behave as women and men (43). Connell, an Australian sociologist, argued that gender is a social construction that can only be understood in relation to social categories such as class, race, and ethnicity (44). Connell's theory of the gender power structure is based on the concept of *hegemonic masculinity* in which patriarchal gendered power relations empower certain men and give them power over other men and subordinate women in our culture (45). This also means that gendered power relations between men and women should be studied within a given society and also between different groups of men and different groups of women. The construction of masculinity is not static but changeable (46). It means that men can both adopt or distance themselves from hegemonic masculinity when it is desirable (47).

Connell stressed different types of masculinities, and the hegemonic masculinity is the dominating and most valued construction of gender in a given society (45). The hegemonic masculinity is characterized by heterosexuality, an emphasis on physical and emotional strength, risk-taking, denial of weakness and vulnerability and so on (48). The pattern of hegemonic masculinity implies that it “-in the long run – guarantees the collective privilege of men” (46). Men and boys try to construct themselves according to the characteristics defined as features of hegemonic masculinity with support from women and girls. Hegemonic masculinity is not characterized by a special kind of men but how men, position themselves through practice (47). Connell also describes other kinds of masculinities for example, the *complicit*

masculinity, which refers to those who do not fulfill the hegemonic standards but gain from hegemonic gendered power relations. The *marginalized masculinity*, which is constructed in relations between men, where some men are subordinated by other men according to dominant structures in the society. Connell argued that masculinities should be studied in different contexts, such as personal lives, interpersonal interactions and the influences of institutions and mass media.

According to Connell, women also seek different norms of femininity in the society, which she calls the emphasized femininity (47). The emphasized femininity strives towards the patriarchal gender order and therefore, Connell implied that the construction of femininity could not be called a hegemonic femininity. The societal norms of femininity are also called a *normative femininity* (49). When society changes the norms of femininity is also affected (50). The ways women and men behave or are capable of behaving have consequences for their gender identities.

De Visser and co-authors have used Bourdieu's concept of symbolic capital in order to describe how masculinity can be used as masculine capital (51, 52). The social capital that an individual holds affects one's ability to deal with various social settings and consists of the individual's knowledge, social connections, experiences, and reputation. These factors are important sources of power and authority. The capital can be invested, lost, stored, and traded. De Visser and co-authors also used Bourdieu's concept of habitus, which suggests that a behavior is formed in relation to a historical perspective that produces norms and habits in a given society. By comparing the masculine capital to the symbolic capital they have shown that different factors of masculine capital have different values. For example, they showed that alcohol consumption was seen as strengthening the masculine behavior, but it was less effective compared with sexuality and sports (52). They also found that it was possible to compensate a non-masculine or a feminine behavior with another masculine behavior. They used the term "man points" and indicated that man points could be gained or lost.

The use of the categories "women" and "men" is complicated. Butler stresses that there is not a worldwide united sisterhood between women or a female community that can generally represent "women" (53). According to Butler's theory of performance, the repeated use of the categories "women" and "men" increases the risk of making them be seen as natural. The frequent use of these categories can also contribute to their confirmation and lock them as normative, and this lead to their interpretation as essential identities. Instead, Butler's argues for deconstructing the normative categories.

Gender and everyday health

In general, it is not hard to find differences between women and men's health. It seems contradictory that women live longer than men when women report more illness and have a higher sick-leave rate compared to men (54). It has been shown in several studies that women in general are described as being more troubled by diseases compared to men (55-57). Men, and especially young men, are also known to seek health-care less often than women, which presumable, is a reason for their shorter life expectancy (58). Men are also known to exhibit more risk-taking behavior than women (48). Because the biological differences between men and women cannot explain all of the differences in health, it has been suggested that part of the explanation can be found in constructions of gender (59). A risk of not studying gender constructions in society is that the patient might not have equal access to treatment if the patient does not fit into the pattern of the disease because of their gender (48, 60).

The individual experiences of living with celiac disease and the effects of the disease on the overall life have been examined by quality of life (QoL) studies (61-65). Those quantitative studies have used various designs to study QoL. Some studies have used questionnaires specially designed for celiac disease, and others have used common and validated questionnaires developed for different age groups. Some studies have measured a single point in time, and others have included repeated follow-up questionnaires. The results from the different QoL studies also differ. Some of the studies show that living with celiac disease has no great impact on overall QoL compared to a non-celiac control group (63, 66). Other studies report individuals having feelings of anxiety, of being a burden and of being stigmatized in meal situations (61, 67, 68). It has also been suggested that the results of quantitative QoL studies are associated with the degree of compliance to the gluten-free diet and with issues related to the gluten-free diet (65, 69). Studies has shown different results, regarding whether women or men are more compliant with the dietary treatment (70, 71). Another suggestion has been that the perceived everyday experience of living with celiac disease is dependent on the circumstances experienced when the individuals received their diagnosis, and whether it was detected through screening or by the appearance of symptoms (25). Other researchers have suggested that the results of the QoL studies are associated with how individuals experience their everyday lives, in terms of psychological features and social relations (72, 73). The experiences of living with celiac disease seem to differ between men and women, and diagnosed women generally report lower well-being than diagnosed men and controls. Diagnosed men report a similar – or even better – well-being compared to

controls (61, 63, 74, 75). It is also common that women are in majority compared to men in studies about celiac disease (61, 63, 65, 76).

Food and gender

The norms in our society suggest that some kinds of food are more linked to women and that other foods are more linked to men (77). Lupton (1), stated that foods are often used symbolically to describe how society looks upon gender. For example, sweets, chocolate, vegetables, fruits, olive oil, and chicken are often seen as feminine; these foods represent whiteness (purity, innocence), attractiveness, and virginity. Red meat, strong cheeses, alcoholic beverages, and fast food such as hamburgers and hot dogs are examples of foods that are seen as masculine; these are seen as “strong-making”. Actions around food are also coded by gender. Women are known to prepare food as nourishment for others, but men are often characterized as not taking healthy food as seriously and eat whatever they like as long as it is enough to keep their manhood functioning properly (1, 78). Femininity is linked with small portions and a slim body, and masculinity is associated with large amounts (1). However, today many men experience body dissatisfaction and the male ideal body shown in fitness magazines contributes to this (79), and will, likely influence the expected masculine food norms in the future.

The complexity of food

Need for nutrients

As mentioned earlier, nutritional deficiency is generally not a problem in Sweden. For an untreated individual with celiac disease it is different, the risk of malnutrition is increased. From a nutritional perspective, the understanding of food consumption, suggests that if a person needs a nutrient, he or she will choose a food that contains the missing nutrient. This attitude has some limitations and underestimates the importance of the individuals own food preferences, habits, and social relations in different contexts (80).

Food choices

When studying factors in everyday life that affect how food choices are made, hunger and satiety are often suggested as dominant aspects, but the situation seems to be more complex than this. In order to understand how food choices are constructed the focus should be both on an individual and a structural

level. The basis for food choices is diverse and includes many different behaviors regarding food. Therefore, the questions of what, when, where, and with whom are helpful to understand the complexity of how food choices are made (81). Food choices are often situational. For example, in a Swedish school dining hall the pupils are offered a free hot school lunch every day. During the lunch, they have to make several choices about whether or not to have, for example, the main course, salad, bread, butter, milk, water, ketchup, and jam and they must also decide how much they will eat of each item. None of these choices are made in a vacuum; they are all influenced by norms in society and the environment, for instance, where to sit down and with whom. It has been suggested by Wansink et al. (82), that most individuals make more than 200 decisions about food every day. For an individual diagnosed with celiac disease, the number of food choices is often limited, and the availability of alternatives is less than for others (38). On the other hand, a diagnosed individual must make recurrent choices in order to remain compliant with a gluten-free diet and to avoid food containing gluten. This means that that they are likely to have to make even more food choices every day.

The food choice process model of Furst et al. (81, 83, 84) describes the dynamics behind the food choice process. The base of the model represents the *life course*, which includes several factors such as growth, life stage, trajectories, transitions, turning points, and contexts. *Trajectories* are the personal values, feelings, persistent thoughts and actions regarding food. In a situation such as the school dining hall, gluten-free foods are often labeled “special diet”, which a responsible individual compliant with a gluten-free diet would have to choose. *Transitions* are times of change, such as when an individual leaves their parents’ home. *Turning points* indicate times, for example when individuals decide to change their diet voluntarily or are diagnosed with a food related disease. The surrounding *context* including family, friends, and community describes the ethnic food culture shared in common gatherings (85-88). In general, food choices should be understood from the perspective of past experiences (81).

Next step in the food choice process model is *influences* (83). This part describes the dynamics of psychological, physiological, and societal factors and their importance in making food choices (81, 83). For example, ideals are constructed rules that are shared by a group and acts as reference points for describing certain foods as right or wrong or as normal or abnormal. Food choices are dynamic, and Robinson and Higgs (89), showed how social information can influence a person’s experience of a food item. They studied young adults who, after being exposed to others with negative feelings about a food item, started to rank their own liking of the food item significantly lower than before (89). This suggests that the perceptions of how others experience

and express their attitude towards food can have implications for how the food is accepted. Olsson et al. (68) showed that adolescents diagnosed with celiac disease sometimes encountered others who stared, joked and talked disparagingly about the gluten-free food and its presumed taste, a behavior that had a negative impact on how they themselves perceived the food. It has also been shown that during adolescence individuals' perceptions about what their peers eat are often incorrect, yet these assumptions often affect what and how much food is eaten (84, 89).

The perceived taste of food is usually seen as an individual experience, and foods are usually described as tasting good or bad (83). Lupton (1), argued that taste is much more complex than just an experience in the mouth. She suggested that by eating certain foods, we present our position in society to others as well as to ourselves (1). So, what does this mean for the pupil in the school dining hall who needs a special diet?

According to Gronow (90), we can “learn to like” the taste of certain foods, which should give hope to those with celiac disease who experience the gluten-free foods as distasteful (76). Gronow also stated that “good taste” can be acquired, and a specific taste could in some ways be used to distinguish individuals from each other (90). Wiggins (87) has shown that experiences of thinking that certain foods are disgusting could have similar implications. The argument is that disgust is more than an individual experience, and it can be transferred between groups or function as a way to create or define boundaries between groups. Food choices are also influenced by access to various “capital,” for example, financial, relational, traditional and social capital and by one's roles in society, such as being a woman, a man, a member of various organizations, or a parent.

The top of the food choice process model is the *personal system*. At this part, the individual develops values in relation to food that are implemented in food choices. This means that the food can be seen as e.g. healthy or unhealthy or as real food, or junk food. These values placed on food are dynamic and can be determined consciously or unconsciously.

Food and meals as symbols

When friends come over for a dinner or when one prepares a birthday cake, food is used as a symbolic gesture that represents values such as affection and friendship (78, 91). When food carries a symbolic value, it is important that the food is common in the culture where it is used and to the individual it is given to; otherwise, the intent could be misinterpreted. It is inappropriate to

give a person with a peanut allergy a peanut cake because it is possible that it could be deadly. For a person with celiac disease, the consequences of eating gluten are less drastic, but it will cause damage to the intestine. It does not show in the appearance on the outside of the body but on the inside it will show (27).

Food choices usually follow the social norms in a given culture in order to gain social approval and be accepted (92). If a person follows the societal recommendations for regular eating habits, the good eating habits symbolize that the person is morally acceptable, if a person exhibits poor eating habits, this can be seen as less moral (78). It has been shown that social meals also can work as an investment in improved relationship (89, 93). This could be done when matching food choices and intakes with people eating similar diets. It can be difficult, or even impossible, however, to match foods in a social situation for a person with a prescribed a gluten-free diet. It has been shown that if a food conflict arises, the relationship is generally placed before a personal food choice. This often involves eating the same food as the others even if such a food would not normally be chosen (84, 89, 93, 94). Such behavior is likely to be a big challenge for those diagnosed with celiac disease, because it could mean that they cannot remain in compliance with their strict diet. It has also been shown that food portion size is affected by the intake of others; if someone joins the table without eating, the portion sizes of the others will become smaller (94, 95).

Objectives

The objectives of this study were to investigate what happens with food choices and nutrient intake when individuals are prescribed a gluten-free diet and to examine the consequences of the diet on the everyday lives of young women and men.

Specific objectives

- To compare the reported energy and nutrient intake in girls and boys with celiac disease diagnosed in early childhood with the reported intake of a non-celiac age-and gender-matched control group and the estimated average requirement (EAR) in the Nordic Nutrition Recommendations (NNR) 2004 (2) (Paper I)
- To explore how celiac disease diagnosed by screening in early adolescence affected overall food choices in comparison with adolescents diagnosed with celiac disease at an earlier age and a reference group of adolescents without celiac disease with similar age- and sex distribution (Paper II).
- To explore the daily experiences of young Swedish women with screening-detected celiac disease in relation to the gluten-free diet five years after the screening (Paper III).
- To give a voice to young men with screening-detected celiac disease and to highlight the situations that they encounter in their daily lives five years after the screening (Paper IV).

Methodology

In order to understand how this thesis has developed during the years a broad perspective of the methodology is given below.

In this thesis both quantitative and qualitative methods have been used, which means that quite different working processes has taken place. In the quantitative studies of papers I and II, participants reported their food intake by a food frequency questionnaire (FFQ) and the data were interpreted with statistical methods. In the qualitative studies of papers III and IV participants were interviewed and the transcribed interviews were analyzed and reflected on from various theoretical perspectives.

This chapter is organized as follows. I first position myself as a researcher and then describe the participants in each of the studies. The quantitative and qualitative methods used in this thesis are briefly described and discussed. More details about the methods can be found in the respective papers.

Positioning myself as a researcher

Donna Haraway is a famous feminist scholar and a professor of science and technology studies. She questions the positivist scientific attitude that she calls the “god-trick,” which is a belief that scientists can place themselves outside of their research and rise above the subject to provide an objective science truth about the world (96). Instead, she argues that the scientific researcher is “in the belly of the monster.” This means that as a researcher, I am a part of my research and am telling a story in which I myself am involved. According to Haraway, when using what she calls a situated knowledge, the researcher should reflect on her or his own situated position and use of tools and to be aware that the findings are only a fraction of reality that is localized in a specific room, time, body, and power relation.

My theoretical standpoints are diverse. When studying to become a dietitian, I cannot recall that I ever considered from what theoretical standpoint we learned about food and nutrition - it was a one-way street. I was mostly taught from the positivist epistemological view common in the natural science field. Positivist epistemology deals with facts. I was taught that by doing empirical research and studying the works of others, we could learn to understand and know how things are. When I studied to become a researcher, I was taught that the confusion I previously had felt (even if hidden), certain that life is more complex than facts, made me see deficiencies with the positivist view.

The rebel inside me did not find satisfaction in the positivistic view. I discovered that there are other theoretical standpoints that could be used in understanding the world. Therefore, in this work I used established quantitative tools for analyzing data, but I also departed from the prominent positivist standpoint and focused on qualitative data, which are problematized and discussed from various theoretical standpoints.

I was born during the 1960s in northern Sweden and raised in a traditional Christian blue-collar household as a girl and a woman. As an adult, I married and had children, studied to be a dietician and today I have grandchildren. Due to my age, sex, and profession, I might have been seen as a parent figure by the young adults interviewed which might could have affected the findings.

Participants

All of the participants in this study took part in the first phase of a Swedish multicenter longitudinal project called Exploring the Iceberg of Celiacs in Sweden (ETICS) in 2005-2006 (17). ETICS was a school-based screening project conducted in five large cities in Sweden and their surrounding municipalities that investigated the prevalence of celiac disease among pupils in the sixth grade, most of whom were born in 1993 (they were about 12-years old at the time when the ETICS study began).

The participants studied in papers I and II were divided into the following four groups based on the results of the screening: the previously diagnosed group (n=66) who were diagnosed with celiac disease by the health-care provider due to symptoms prior to the screening at a median age [25th - 75th percentile] of 1.5 [1.0-8.3] years for girls and 1.6 [0.9-9.3] years for boys: the screening-diagnosed group (n=144): and two randomly selected sex- and age- matched non-celiac control groups, one of which was used for baseline comparisons (n = 1,151) and one that was used for follow-up comparisons (n = 828).

In papers III and IV, nine young women and ten young men were invited to be interviewed. Seven women and seven men accepted the invitation. Criteria for being selected were participation in the ETICS 2005-2006 screening and diagnosed with celiac disease through the screening, sex, and having remained in the same geographical area. At the time of the interviews they were 17-18 years old.

To indicate the time difference between the screening procedure and the interviews, the participants are referred to as adolescents when they were

screened at the age of 12-years old and as young adults or young women and men when they were interviewed at 17-18 years old. (Figure 1.)

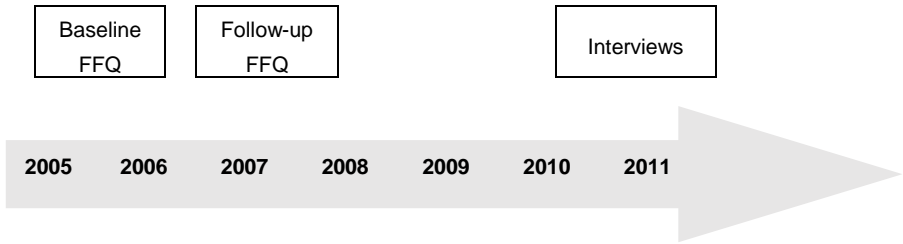


Figure 1. The timeline for the data collection in this study.

Quantitative methods for papers I and II

Study design of paper I

In paper I, we completed a nested case-control study (Figure 2). The data were obtained from the baseline FFQ from the first phase of the ETICS screening study. The previously diagnosed group and the baseline non-celiac control group reported their food intakes during the previous four weeks. The findings are reported by group and by sex.

In the findings, macronutrient intake is presented as absolute intake (g/day) and as energy percent (E%) with the exception of fiber, which is presented as g/day and g/MJ. The intake of vitamins and minerals is presented as nutrient density, which is the amount of reported intake per 4.184 MJ, and as a proportion of the EAR based on the NNR 2004 (2).

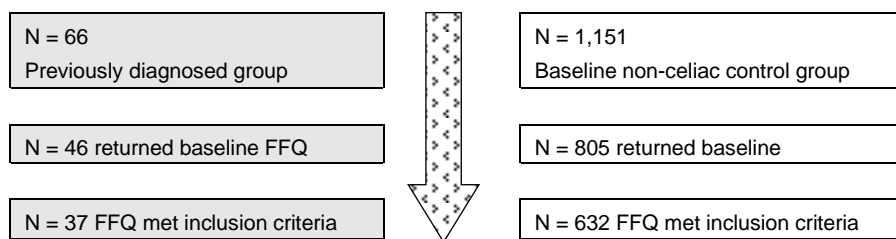


Figure 2. Overview on the study design in paper I, the grey boxes symbolize the prescribed gluten-free diet and the white represent eating regular diet.

Study design of paper II

In paper II, we completed a longitudinal study (Figure 3). The screening-diagnosed group completed the baseline FFQ before they had received the result of the screening for celiac disease. They completed the follow-up FFQ after they had begun with the gluten-free diet. Data from the previously diagnosed group and the screening-diagnosed group were used only if the individuals returned both the baseline and follow-up FFQs and both FFQs fulfilled the inclusion criteria described below. Because the baseline and follow-up control groups consisted of different participants, food intake was not reported as a change over time but as a comparisons between groups.

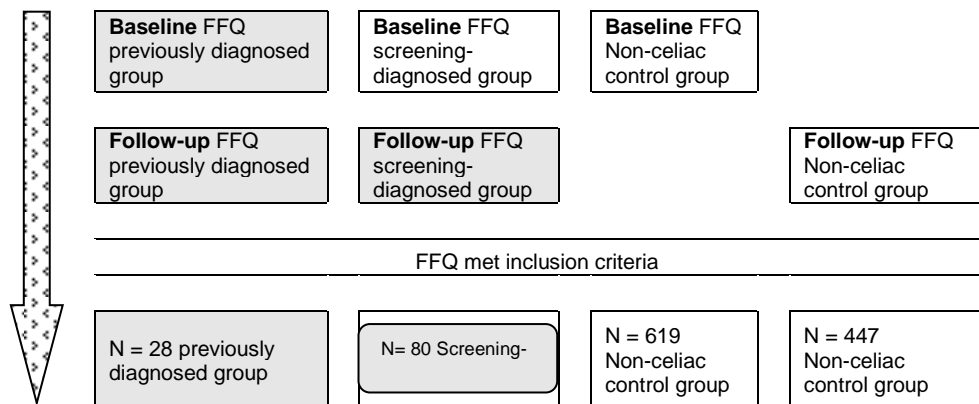


Figure 3. Overview of the study design in paper II. The grey boxes indicate participants who were prescribed a gluten-free diet, and the white boxes represent eating regular diet.

Dietary assessment method

The FFQ was specifically designed for the ETICS study by dietitians, health-care personnel, and researchers. The main purpose of the FFQ was to get an overview of food intake and to study the intake of food containing gluten. The FFQ was written in Swedish and was pretested with adolescents of the same age and their parents. The accompanying letter encouraged the participants in the study to complete the FFQ together with their parents. The baseline FFQ was almost the same for participants with celiac disease and participants who had not been diagnosed with the disease. The only difference was that the celiac-diagnosed group self-reported their adherence to the gluten-free diet by answering specific questions about how often the foods they consumed were gluten-free in relation to foods that normally contain gluten, (e.g. bread and pasta).

The FFQ included questions about consumption frequency and average quantity consumed of 57 food items or common food groups. Household measures and a color photograph booklet, made by the Swedish National Food Agency (97), were used to estimate portion sizes. Registered dietitians converted the frequencies and volumes reported in the FFQ to g/day and nutritional intake was calculated using the software program Dietist XP 3.1 (Kost och Näringsdata, Bromma, Sweden, version 2010-06-18) based on the Swedish National Food Agency database (version 2010-03-15).

A similar FFQ was sent out 12-18 months later in the follow-up study. Both the previously diagnosed and the screening-diagnosed celiac disease groups received questions about how often they consumed gluten-free versions of products that normally contain gluten. Questions about supplements and physical activity were also added.

In search of reliable quality of the reported food intake

The overall aim when food intake is being studied is that the participants should eat as they normally do and report their accurate intake. This seems like a reasonable expectation, but when working with food issues, past experience shows that this is not an easy task. Therefore, some precautions were taken before the start of the analysis in order to assess the quality of the data. The returned FFQs were scrutinized, and those not meeting the quality standards were excluded. FFQs were excluded if they were not adequately filled in or were defined as unrealistic, that is, when the reported food intake level (FIL), which is the reported energy intake divided by basal metabolic rate

(BMR), was below the 5th percentile ($FIL < 0.9$ for both girls and boys) or above the 95th percentile ($FIL > 2.7$ for girls and > 2.9 for boys) (18, 21).

In paper II, if the returned follow-up FFQ lacked information, the participant's parents were contacted by phone and asked if they could contribute an answer. This resulted in a very low exclusion of participants due to missing data.

Comparing nutrient intake with EAR (paper I)

The risk for inadequate intake of vitamin and minerals was assessed by calculating the EAR based on age and sex (2). The proportion with an intake below the EAR in a group gives a good estimation of the percentage at risk of having an inadequate intake.

The EAR for children was calculated for vitamin A (retinol equivalents), vitamin E (tocopherol), thiamine, riboflavin, niacin equivalents, vitamin B6, folate, vitamin B12, and vitamin C, and for the minerals iodine, phosphorus, selenium and zinc using a two-step extrapolation from adult data as described by Prentice (98).

Classification of food groups (paper II)

For the analysis of food intake after a prescription of a gluten-free diet, food groups were created with a special focus on gluten-containing food items and their gluten-free counterparts (Table 1). This resulted in two main groups of food: grain containing, and non-grain containing. The food group "pastries" was placed under grain products when counted separately but under non-grain products when included in discretionary calories (which included sweets, snacks, ice-cream, pastries, soft drinks, sweet dessert soups, and jam). To enable comparisons between individuals regardless of their energy intake, all dietary intakes were converted to intake gram per 4, 184 KJ (1,000 kcal) which is common practice.

Table 1. Definitions of food groups in paper II.

Food Group	Description
<i>Grain Products</i>	<i>Both gluten-containing and gluten-free</i>
Bread _{total}	Soft and crisp
Bread _{low fiber}	Low fiber
Bread _{whole grain}	Soft bread labeled with the Swedish “keyhole” symbol indicating high fiber or wholegrain content
Crisp bread	
Cereals _{total}	All products where cereals constitutes a main ingredient and their gluten-free substitutes
Breakfast _{cereals}	Breakfast cereals, porridge
Pastries	Cookies, cake, buns
Pasta	Pasta, couscous, bulgur pearl-barley
Pizza	
Pancakes	
Fish fingers	Breaded fish
Chicken nuggets	Breaded chicken
<i>Non-grain products</i>	
Fruit	Fruits, berries, dried fruits
Vegetables	Vegetables, root vegetables (not potatoes)
Potatoes	Potatoes, French fries (not potato crisp)
Dairy	Milk, milk products, cheese
Fat _{as spread}	Butter, margarine
Eggs	
Meat _{total}	Meat, processed meat products (i.e. sausages, meatballs, cold cuts)
Meat processed	Processed meat products (i.e. sausages, meatballs, cold cuts)
Fish _{total}	Fish, shellfish, processed fish products
Poultry _{total}	Poultry, processed poultry products (i.e. sausages, meatballs, cold cuts)
Rice	
Discretionary calories	Sweets, snacks, ice cream, pastries, soft drinks, jam, dessert soups

Body measurements

The height and weight of all participants were measured in light clothing during the screening in the schools on average seven months (range 2-16 months) before the adolescents filled in the baseline FFQ. The height and weight of the screening-diagnosed celiac disease group were also repeatedly measured at follow-up visits at hospitals. For the other groups, no further measurements were made. To enable calculations of BMR (which is based on age, sex, weight, and height) at the time of filling in the FFQs, approximations of weight and height were calculated based on z-scores and the assumption that the adolescents with previously diagnosed celiac disease and the healthy controls did not deviate from their growth curve. The gender and age - specific z-scores for height and weight were calculated based on US national reference data from the Center for Disease Control (99). For the screening-diagnosed group, weight and height measurements taken at hospitals nearest in time to the FFQ were used. An individual BMR was calculated using Schofield's equation based on weight, height and sex for ages 11-18 years (100). The body mass index (BMI) was used to determine if the participants was overweight or obese according to Cole's international age and gender-adjusted cut-off values for adolescents (101).

Energy adjustment

To enhance the understanding of the data, low-, adequate, and high energy reporters were assessed using Goldberg's equation (102). Each individual's calculated FIL was compared with an estimated physical activity level (PAL) for the total group in order to measure how plausible the reported energy intakes were (102). The calculated PAL was based on data from the follow-up FFQ, in which questions about physical activity at school and during leisure time had been added. The majority, 70% in the celiac disease-group and 72% in the non-celiac control group, were defined as adequate energy reporters. All statistical analysis were performed with both the total sample and with only the adequate reporters. Differences in anthropometry and dietary intake between the groups showed similar patterns (although this was somewhat attenuated when only the adequate reporters were included). Therefore, the results are presented for the total sample.

Statistical analysis

The statistical program IBM SPSS Statistics 19 was used when processing the data for paper I and paper II.

In paper I, Kolmogorov-Smirnov statistic test was performed to test for normal distribution. Differences between groups were tested with Student's t-test when variables were normally distributed and with Mann-Whitney U-test when they were not. The variables BMI and intake in relation to the EAR were recoded to categorical variables in order to perform Chi-square tests. Data are presented as mean \pm 1 one standard deviation (SD) and as median (25th - 75th percentiles).

In paper II, the amounts eaten and the proportions of participants eating a specific food group were studied both at baseline and at follow-up. Kruskal Wallis test was used to analyze both the proportions and the differences between groups at baseline and at follow-up. The Mann-Whitney U-test was used to analyze differences between the non-celiac control groups and differences between the screening-diagnosed group, the previously diagnosed group and the non-celiac control group at baseline and at follow-up. The Wilcoxon signed-rank test was used to analyze changes in food intake between baseline and follow-up in the screening-diagnosed and previously diagnosed groups. The level of significance was set at $p < 0.05$.

Effect size

Attention is easily drawn to a statistical test that shows statistical significance. A result that is statistically significant, however needs further analysis (103). The use of effect size allows a deeper interpretation of the result because it deals with the risk of mass-significance caused by performing many tests and reduces the influence of the sample size (104). When differences in a group with many participants are small, unimportant differences can become statistically significant. On the other hand, when differences in a small group are calculated and shown to be non-significant, the effect size can show that the effect of the differences is large and can signal that further research should be undertaken before any strong conclusions can be drawn from the results (103, 104). Depending on what data had been compared, interpretation of the calculation of effect size was done according to Cohen's definition from 1988, described by Pallant (104). For simplicity, *effect size* is expressed by the capital letters VS, S, M, and L, regardless of the reference used. The term very small (VS) was used when the effect size was lower than the estimated small effect size (S). The letters M and L correspond to medium and large effect size, respectively.

Considerations about the quantitative methods

The results from paper I and II rest on analyses that we considered as well-founded in several aspects, but there are limitations.

Food surveys are difficult because the participants must have some awareness of their food intake, and be willing to report their intake and the food consumed must be an option that can be chosen in the FFQ (105). The pretest of the FFQ was performed to deal with the latter issue, but an FFQ can never cover the entirety of an individual's food choices. Other difficulties with dietary assessments in general, are that food intakes usually change over the seasons and by age (106). Strengths with the data collection for paper I and II are that the participants in the studies were the same age, all groups filled in similar FFQs during the same periods and the studies were population based, none of which are common in studies about celiac disease and food intake (28, 29). A limitation is that the baseline and follow-up FFQ were not answered during the same season.

The FFQ was designed according to the purpose of these studies and specifically for the participants involved, which is known to be very important in food surveys (107). A limitation is that although the FFQ was pretested, it was not validated. However, the FFQ contained questions about both the amount and frequency of food intake, which is a strength, as is the broad range of the response alternatives (107). The participant also had the option to use a food picture book or house-hold measurements to report the accurate amount of food intake (97). Criteria were set related to how often and how much of the reported intake was allowed to be missing for an FFQ to be included in the analysis.

It is common in food surveys for participants to over- or under-report their food intake (108). The use of doubled labeled water (DLW) method, which is considered the gold standard for validation of energy intake (109), might have been helpful to measure how well the reported intake matched the real intake, but it is very expensive and was beyond the means of this thesis. However, an FFQ is not meant to capture the full intake, which makes the DLW method less useful. Instead, an individual FIL was calculated. Studies of reported food intake should be done in relation to physical activity (102). Therefore, in paper II, an individual PAL was estimated from the participants' reported activity levels at follow-up. In paper I, the mean group PAL from the follow-up was used because physical activity was not reported at baseline, and it was deemed more appropriate to use the group mean from follow-up rather than using

standard values for age and sex. Accelerometers could have given a more accurate measures of the individual physical activity than filling out a questionnaire, which the participants did in the follow-up FFQ (110). However, this was not feasible due to the large number of participants.

The reported food intake in paper I was compared with the EAR, which is the accepted way to evaluate dietary intake (111). In several studies on dietary intake in celiac disease, reported intake is only compared with nutrient recommendations. Such comparisons are likely to give misleading results with regard to the risk for deficiencies because all nutritional recommendations (except for energy) are set with a safety margin for the general population, usually the EAR plus two SD, to ensure that the recommendation covers the nutrient need of 97.5% of a population.

New data from the Swedish National Food Agency was used in the analysis when measuring nutrient intake in the gluten-free products. This is important because it is likely that the nutrient content in products can change with new techniques and recipes. However, the nutritional value of home-baked gluten-free bread was uncertain, because the kind of flour used when baking was not declared in the FFQ.

In all papers in this thesis, the strict gluten-free diet is mentioned. In the FFQ (papers I, and II), we asked the adolescents with celiac disease to self-report how strictly they followed the gluten-free diet. This method should be considered as a blunt measurement of compliance (71).

In paper II, changes in food were studied between the reported intake at baseline and follow-up, and food groups were designed with a primary focus on gluten-containing products. In general, the purpose of a specific study sets the criteria for how food groups are chosen, which makes it difficult to compare different studies (112, 113).

The number of participants in each group was very different. The previously diagnosed group was the smallest, about half the size of the screening-diagnosed group, which reflects the “iceberg metaphor” often used for celiac disease (114). The non-celiac control groups were significantly larger than the two celiac groups due to the greater scope of the ETICS study. The dietary part of the ETICS study was only one of several sub-studies. Some of the other studies had a greater need for many controls per case, so by extension, this study also had many controls. Because many tests were performed in the statistical analysis in paper I and II, effect size was calculated to deal with the risk of mass-significance and the different group sizes. This allowed us to

further interpret the statistical results instead of just highlighting the results showing statistical significance without further consideration.

One limitation is that in paper II the adolescents were classified as one homogenous group. Therefore, food intake at baseline and follow-up could not be studied in relation to sex. This means that similarities and differences with regard to food changes over time between genders were not studied.

Qualitative methods for papers III and IV

Study design of papers III and IV

The participants in papers III and IV received an invitation letter, were accepted to be interviewed, and the interviews took place. All interviews were transcribed verbatim and read through repeatedly during the analysis by the first author. The content analysis method described by Graneheim and Lundman (115) was used when analyzing the data. Graneheim and Lundman (115) stated in their paper about content analysis that they make the assumption that reality can be understood in different ways and that the interpretation is subjective. Therefore, the analysis has to be performed and discussed in depth when doing content analysis. All interviews were read through by three of the co-authors at least once. This is a strength of the analysis because a text always has various meanings and can be interpreted in different ways. After completing the interviews, the decision was made to analyze the interviews of the young women and men separately because the material was considered rich.

In paper III, different practical strategies were tried out to sort the data into codes in order to have “tools to think with” (115). Cutting paper with text from the interviews and using the word-processing program Word were practiced, but finally the spreadsheet program Excel was chosen as the most functional way to handle the data. In paper IV the software program ATLAS.ti was used when creating codes and categories. For both papers, meaning units, condensed meaning units, codes, categories, sub-themes, themes, and main themes were discussed during several meetings with the co-authors until consensus was achieved.

The analysis had a manifest focus up to the sub-theme level and then the findings were interpreted by other theoretical premises that, resulted in latent main themes for both papers III and IV. The formulation of the themes was based on the tone of the interviews. The young women presented themselves

as rather passive, and the young men presented themselves as active. The results were reflected upon according to various theoretical perspectives. Connell's theory of gender constructions was used to illustrate the implications that gender has in the everyday lives of young women and men diagnosed with celiac disease. De Visser et al. description of "man points" was used to describe how fluid masculinities can be constructed. Foucault's theory of power was used to illuminate power relations between the dominant medical paradigm (which also includes dietitians) and patients' own narratives and experiences.

Considerations about the qualitative methods

Papers III and IV aimed to highlight how the everyday lives of young women and men are affected by a diagnosis of celiac disease. By dividing the women and men, there is an increased risk of reproducing differences between young women and men as if they were static and unchangeable. However, the differences were obvious. Therefore, the interviews were splitted according to gender in the analysis. It is important to stress that there were also similarities in the young women and men's narratives. It is important to bear in mind that the gender order is constructed by society and is, therefore, likely to differ over time and between cultures.

In order to interpret the trustworthiness of the findings in papers III and IV, content analysis labels such as credibility, dependability, and transferability were used (115). These labels were used to describe the relationship between how the analysis had been performed and how the analysis led to the formulated themes in each of the studies. Credibility deals with whether the choice of participants, context, and gathering of data were in accordance with the research question. The participants in the interviews were born in the same year, lived in Sweden, and all took part in the screening study where they had been identified as having celiac disease. Credibility was also achieved through recurring meetings with co-authors, where material and the representative citations were discussed. Dependability deals with how time influences the gathering of the data and how the researcher deals with the new insights that inevitably emerge when doing interviews. In papers III and IV, all the interviews took place from winter to spring in a school year, a period of seven months from November to the end of May. The semi-structured interviews followed predetermined questions, although the order and the formulations of the questions were adjusted to the participant's story.

Only seven participants each were interviewed for papers III and IV, and this could be seen as too few to draw any conclusions from the data. However, by making theoretical points and referring to previously published data, the findings are strengthened and should be given attention in order to give appropriate support to young women and men with celiac disease. The use of different theoretical premises enables the interpretation of the narratives and broadens the picture of the understanding of how young women and men live with celiac disease in a Swedish context. However, qualitative studies do not claim that they are transferable to everybody else in every context. Therefore it is up to the reader to decide if the findings are transferable to other contexts (115).

Ethical Considerations

This study was conducted according to the guidelines in the Declaration of Helsinki and all procedures involving human subjects and patients were approved by the Regional Ethical Review Board in Umeå. Papers I and II had approval number, Dnr 04-156M and papers III and IV had approval number Dnr 2010-110-31 M. Written informed consent was obtained from all participants. The participants could at any time discontinue their participation. In papers I and II, each individual was assigned a code that temporarily replaced the personal identity number, and security for the database was high, with access only available to key researchers.

Before the interviews for papers III and IV took place and before the participants signed the written consent, they were reminded of their rights, and that the content of the interview would be handled confidentially. During the analysis the interviewed were given a number which replaced the individual name and location.

Findings

The participant characteristics from the FFQs that remained after applying the inclusion criteria for papers I and II are summarized in Table 2 and 3, respectively.

The comparisons of the participants' body height and weight in paper I showed that the previously diagnosed celiac disease group members were slightly shorter and lighter than those in the non-celiac control group. The calculated effect size showed only small or very small differences between the groups despite being statistically significant.

In paper II only participants who returned an FFQ that met the inclusion criteria at both time points were included. The comparisons at a group level showed that a diagnosis of celiac disease did not seem to affect height and weight when comparing the screening-diagnosed celiac group, previously diagnosed celiac disease group, and the non-celiac control groups at baseline or follow-up.

The self-reported compliance showed that most of the participants strived to be compliant with the gluten-free diet whether diagnosed by clinical symptoms or by screening.

Nutrient intake (paper I)

Differences between the girls and the boys

Divided by gender, the analysis of nutrient intake at baseline revealed that most of the girls and boys in both the previously diagnosed group and the non-celiac control group reached the recommended intake for micronutrients, as shown in Figure 4 and 5. In both groups of girls, the largest percentage had a Vitamin C intake below the EAR. Among the boys with celiac disease, the largest percentage did not reach the EAR of thiamine intake. The percentages of boys below EAR of vitamin C were also very similar to girls.

Table 2. Descriptive characteristics of 13-year-old adolescents previously diagnosed with celiac disease (CD, 23 girls and 14 boys) in early childhood and a non-celiac control group (NC, 342 girls and 290 boys) Sweden 2006-2007.

Control group (NC, 342 girls and 290 boys), Sweden 2000-2007.												
	Previously celiac diagnosed (CD)			Non-celiac baseline controls (NC)			CD vs. NC			All		
	Girls N = 23	Boys N = 14	Girls	Girls N = 342	Boys N = 290	Girls	Girls	Boys	CD	NC	CD	
	Mean ± SD		vs.	Mean ± SD		vs.			Mean ± SD		vs.	
	Median (25 th , 75 th percentile)		boys	Median (25 th , 75 th percentile)		boys			Median (25 th , 75 th percentile)		NC	
Weight	47.3 ± 13.1	42.3 ± 7.4	NS ¹	48.7 ± 9.7	47.5 ± 11.1	* ¹	NS ²	NS ²	45.4 ± 11.4	48.1 ± 10.3	* ²	
kg	43.0 (40.8, 53.7)	40.0 (36.3, 48.5)	S ³	47.1 (42.0, 54.0)	45.6 (39.5, 52.0)	S ³	S ³	S ³	43.0 (38.4, 49.3)	46.6 (41.0, 53.0)	S ³	
Height	156 ± 8	154 ± 9	NS ¹	158 ± 7	158 ± 9	NS ²	NS ²	NS ²	155 ± 8	158 ± 8	* ¹	
cm	157 (151, 161)	150 (147, 163)	S ⁴	159 (154, 163)	157 (152, 163)	S ³	S ³	S ³	156 (149,162)	158 (153, 163)	VS ⁴	
HAZ⁵	0.1 ± 1.1	-0.1 ± 1.1	NS ¹	0.5 ± 1.0	0.5 ± 1.1	NS ¹	* ¹	NS ¹	0.05 ± 1.1	0.53 ± 1.0	** ¹	
	0.2 (-0.7, 0.9)	-0.3 (-0.9, 1.0)	VS ⁴	0.6 (-0.1, 1.2)	0.5 (-0.1, 1.2)	VS ⁴	S ⁴	S ⁴	0.1 (-0.8, 0.9)	0.6 (0.1, 1.2)	S ³	
WAZ⁵	0.0 ± 1.2	-0.3 ± 0.8	NS ²	0.3 ± 0.9	0.2 ± 1.0	NS ¹	NS ²	* ²	-0.1 ± 1.1	0.3 ± 0.9	* ¹	
	-0.1 (-0.7, 1.0)	-0.5 (-0.9, 0.4)	S ⁴	0.4 (-0.2, 1.0)	0.3 (-0.5, 0.8)	VS ⁴	S ⁴	S ⁴	-0.2 (-0.8, 0.5)	0.3 (-0.4, 0.9)	VS ⁴	
BMR⁶	5.8 v ± 1.0	6.1 ± 0.6	** ²	5.8 ± 0.6	6.5 ± 0.8	*** ²	NS ²	NS ²	5.9 ± 0.9	6.1 ± 0.8	* ²	
	5.4 (5.3, 6.1)	6.0 (5.6, 6.6)	M ³	5.6 (5.4, 6.1)	6.4 (5.9, 6.8)	L ³	S ³	S ³	5.6 (5.4, 6.2)	5.9 (5.5, 6.5)	S ³	

BMR, basal metabolic rate; HAZ, height for age z-score;; N, number; NS, not significant; SD, standard deviation; WAZ, weight for age z-score

¹Differences between groups analyzed with Students *t*-test, **p* <0.05, ***p* <0.01, ****p* <0.001.² Differences between groups analyzed with Mann-Whitney U-test, **p* <0.05, ***p* <0.01, ****p* <0.001. ³ Effect size, *r*-value < 0.1= VS (very small) ≥0.1 S (small), ≥0.3 M (medium), ≥0.5 L (large) ⁴ Effect size, eta square <0.01= VS (very small), ≥0.01 S (small), ≥0.06 M (medium), ≥0.14 L (large). ⁵ Calculated with data from reference population from Centers for Disease Control and Prevention. ⁶ Basal metabolic rate.⁷

Table 3. Descriptive characteristics of participants in paper II. All data are presented as mean values (SD) and median values [25th, 75th percentiles], unless otherwise stated.

	Screening celiac diagnosed		Previously celiac diagnosed		Non-celiac controls		p-value†	
	Baseline N = 80	Follow-up N = 80	Baseline N = 28	Follow-up N = 28	Baseline N = 619	Follow-up N = 447	Base- line	Follow- up
Age,	13.1 (0.3)	14.6 (0.3)	13.3 (0.4)	14.5 (0.2)	13.2 (0.4)	14.6 (0.4)	0.115 ^a	0.328 ^a
Years	13.1 [12.9, 13.3]	14.6 [14.4, 14.7]	13.3 [13.0, 13.6]	14.6 [14.4, 14.7]	13.2 [12.9, 13.4]	14.6 [14.3, 14.8]		
Sex F	49 %	49 %	61 %	61 %	54 %	58 %	0.499	0.283 ^b
HAZ	0.4 (1)		0.3 (1)		0.5 (1.0)	0.5 (1.0)	0.457 ^a	
	0.3 [-0.3, 1.1]		0.2 [-0.6, 0.9]		0.5 [-0.1, 1.2]	0.6 [-0.3, 1.1]		
WAZ	0.2 (1)		0.1 (0.9)		0.3 (0.9)	0.3 (0.9) [#]	0.537 ^c	
	0.2 [-0.3, 0.8]		-0.1 [-0.7, 0.8]		0.3 [-0.4, 0.9]	0.3 [-0.3, 0.9] [#]		
BMIZ	-0.01 (1.1)		-0.1 (0.9)		0.1 (1)	0.1 (0.9) [#]		
	0.02 [-0.5, 0.6]		-0.3 [-0.8, 0.6]		0.1 [-0.6, 0.73]	0.1 [-0.5, 0.7] [#]		
PAL[§]		1.8 (1.8)		1.8 (0.1)		1.79 (0.15)		0.694 ^a
		1.8 [1.7, 1.9]		1.8 [1.7, 1.9]		1.75 [1.67, 1.88]		
FIL	1.6 (0.4)	1.6 (0.5)	1.7 (0.5)	1.6 (0.4)	1.6 (0.42)	1.54 (0.44)	0.340 ^a	0.730 ^a
	1.5 [1.3, 1.9]	1.5 [1.2, 1.9]	1.7 [1.3, 2.0]	1.5 [1.3, 1.9]	1.5 [1.3, 1.9]*	1.5 [1.2, 1.8]*		
L/A/H	17/58/5	26/49/5	4/22/2	7/20/1	107/472/40	158/265/24	0.720 ^b	0.556 ^b
EI 								

SD, standard deviation; F, females; HAZ, height for age z-score, WAZ, weight for age z-score, BMIZ, Body Mass Index z-score; PAL, physical activity level; FIL, food intake level; L/A/H, EI low/acceptable/ high energy intake. †Between the three groups: ^a Calculated by ANOVA; ^b Calculated by Chi-square test; #N = 446
^c Calculated by Kruskal-Wallis test. § Measured at ETICS-diet at follow-up, | Assessed by means of Goldberg's cut-off.

Differences between groups, baseline to follow-up, analyzed with Student t-test for independent samples for normally distributed variables, Mann-Whitney U-test for skewed variables, and Chi-square test for normal variables.

The previously diagnosed group reported a lower nutrient intake for both sexes compared to the non-celiac control group (Table 4, 5). The previously diagnosed girls reported a lower intake of thiamine, riboflavin, niacin equivalents, phosphorous, magnesium, zinc, and selenium. Several of the differences were significant compared with the girls in the non-celiac control group. However, the calculation of effect sizes revealed that the differences were small, except for magnesium for which the effect size was large. When comparing the nutrient intake between the boys in both groups the analysis revealed a significantly lower reported intake of thiamine, niacin equivalents, B6, folate, magnesium, iron and zinc, by boys in the celiac diagnosed group.

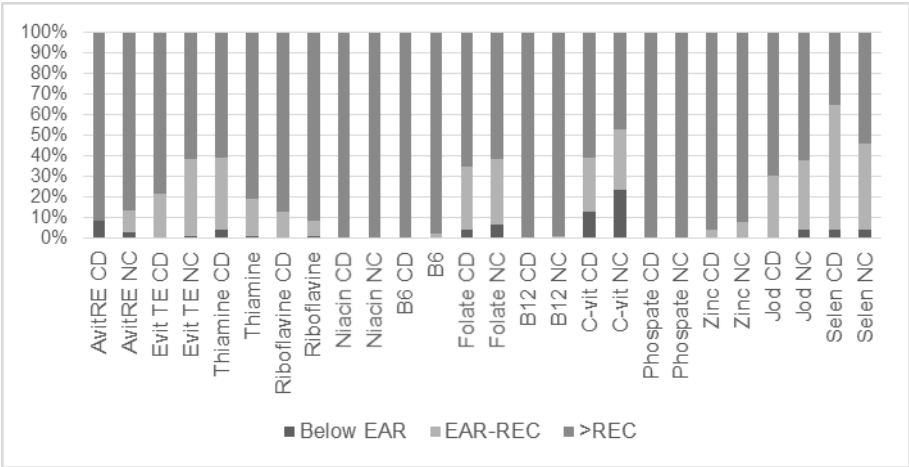


Figure 4. Percentages (%) of girls in the previously diagnosed celiac disease (CD n = 23) and in the non-celiac control group (NC n = 342), reporting a dietary intake below the estimated average requirement (EAR), between the EAR and the recommended dietary allowance (RDA), and above the RDA for vitamins and minerals. Sweden in 2005-2006. Differences between the girls were analyzed using chi-square test.

Only a few girls and boys reported an intake of saturated fatty acids and dietary fiber in line with the recommendations, whether they had celiac disease or not. Most had a higher intake of saturated fat and a lower intake of fiber compared to the recommendations (Table 5).

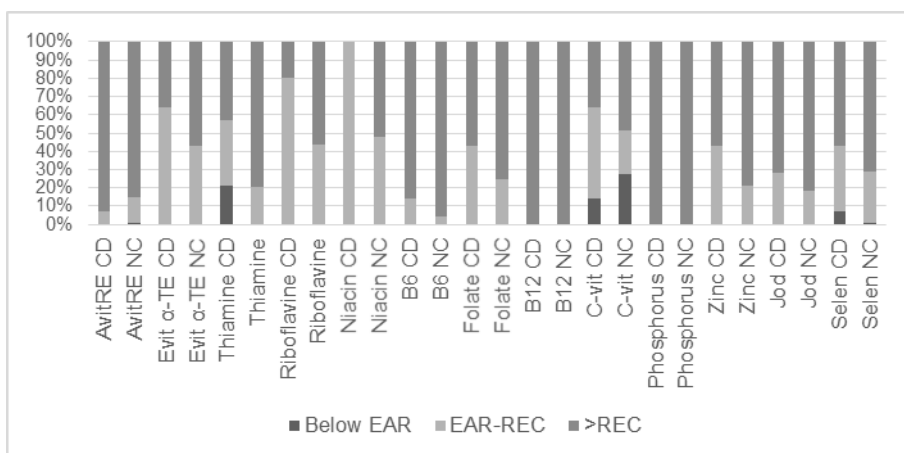


Figure 5. Percentages (%) of boys in the previously diagnosed celiac disease (CD n = 14) and in the non-celiac control group (NC n = 290), reporting a dietary intake below the estimated average requirement (EAR), between the EAR and the recommended dietary allowance (RDA), and above the RDA for vitamins and minerals. Sweden in 2005-2006. Differences between the boys were analyzed using the chi-square test.

When comparing the boys and girls in the previously diagnosed group, the results revealed that the boys reported a significantly lower intake of fiber (g/MJ), effect size L (Table), vitamin C, effect size: M and iron, effect size: L (Table 4). A similar comparison in the non-celiac group showed several significant differences in nutrient intakes but the calculated effect size revealed that most differences were VS or S.

Reported food intake from baseline to follow-up (paper II)

Reported intake of bread

At baseline the lowest intake of bread (g/day) was reported by the screening-diagnosed celiac group at baseline before they were diagnosed (Table 6). One participant did not eat any bread at all. At follow-up, after they had been diagnosed and had begun the gluten-free diet, all screening-diagnosed participants reported some intake of bread, but their reported intake of low-fiber bread, total cereals, pastries, and pizza decreased even further.

Although the screening-diagnosed group decreased their mean intake (g/day) of *low-fiber bread* on a group level, there was an increase in the number of participants that reported that they ate low fiber bread at follow-up. The number of participants that reported that they ate low fiber bread went from 65 to 76 of the total 80 participants, whole-grain bread eaters increased from 53 to 65, and crisp-bread eaters increased from 50 to 58. Fourteen participants in the screening-diagnosed celiac group refrained from eating crisp bread at both baseline and follow-up.

The previously diagnosed celiac group reduced their overall intake (g/day) of crisp bread and pastries from baseline to follow-up. However, they reported the highest intake of bread at both time points and all reported that they ate bread at both baseline and follow-up, which could explain the higher fat intake they reported at baseline compared to the other groups. At baseline low-fiber bread intake was reported by 21 participants. At follow-up, all 28 previously diagnosed participants ate low-fiber bread. Intake of whole-fiber bread was reported by 21 participants at both baseline and follow-up. Crisp bread eaters decreased from 50 to 21 to 17.

All participants in both of the non-celiac control groups reported that they ate some kind of bread. There were fewer in the non-celiac disease control group at follow-up who reported that they ate low-fiber bread and whole-grain bread compared to the non-celiac control group at baseline, but there were more in the follow-up group who reported that they ate crisp bread compared to the baseline control groups.

Reported intake of other food groups

The screening-diagnosed celiac group reported at follow-up a significantly reduced intake (g/day) of pizza, fish fingers, chicken nuggets, and sources of discretionary calories and an increased intake of rice, eggs, and processed meat (Table 7). The estimated effect size revealed that the differences for pizza, chicken nuggets, processed meat and discretionary calories were of medium effect size, and the reduction in pastries was of large effect size.

The proportions of participants reporting an intake of fish fingers and chicken nuggets decreased in both celiac-groups between baseline and follow-up. Eating fish fingers was reported by more than 50% of the participants in both celiac-groups and in the non-celiac disease control group at baseline.

Table 4. Micronutrient intake expressed as amount/4.2 MJ by 13-years-old with celiac disease (CD) since early childhood (23 girls and 14 boys) and non-celiac control group (NC) (342 girls and 290 boys). Sweden 2006-2007.

Nutrient	Previously diagnosed (CD)			Non- celiac control group (NC)			CD vs NC			All	
Recommen- dation ¹	Mean ± SD		Girls	Mean ± SD		Girls				Mean ± SD	CD
	Median (25 th , 75 th percentile)		vs.	Median (25 th , 75 th percentile)		vs.				Median (25 th , 75 th percentile)	vs.
	Girls N = 23	Boys N = 14	boys	Girls N = 342	Boys N = 290	boys	Girls	Boy	CD N = 37	NC N = 632	NC
Thiamine	0.5 ± 0.1	0.4 ± 0.1	NS ²	0.6 ± 0.1	0.6 ± 0.1	[*] 3	^{***} 3	^{***} 3	0.5 ± 0.1	0.6 ± 0.1	^{***} 3
mg, 0.5	0.5 (0.4, 0.5)	0.4 (0.3, 0.5)	S ⁴	0.6 (0.6, 0.7)	0.6 (0.6, 0.7)	S ⁵	M ⁵	S ⁴	0.5 (0.4, 0.5)	0.6 (0.6, 0.7)	S ⁵
Folate, µg,	102 ± 20	90 ± 18	NS ³	109 ± 26	107 ± 28	NS ³	NS ³	^{**} 3	98 ± 19	108 ± 27	[*] 3
92/ 82	98 (88, 114)	86 (73,103)	M ⁵	104 (94, 119)	104 (92, 114)	VS ⁵	S ⁵	S ⁵	96 (82, 109)	104 (93, 117)	S ⁵
Vit.C, mg	28.2 ± 12.3	18.6 ± 4.3	^{**} 2	27.2± 16.2	21.8 ± 10.5	^{***} 3	NS ³	NS ³	24.6 ± 11.0	24.7 ± 14.1	NS ³
22.9/ 20.4	26.0	17.9	M ⁴	23.2	19.9	S ⁵	VS ⁵	S ⁵	21.3	21.5	S ⁵
	(17.5, 38.0)	(15.1, 21.6)		(16.7, 32.5)	(14.8, 26.9)				(15.7, 30.3)	(15.9, 29.7)	
Iron, mg	5.2 ± 1.0	4.5 ± 0.9	[*] 2	5.2 ± 1.1	5.1 ± 1.0	NS ³	NS ³	[*] 3	4.9 ± 1.0	5.2 ± 1.0	NS ³
5.0/ 4.5	5.4 (4.4, 6.0)	4.6 (3.7, 5.0)	L ⁴	5.0 (4.5, 5.8)	5.1 (4.5, 5.6)	VS ⁵	S ⁵	S ⁵	4.8 (4.0, 5.7)	5.1 (4.5, 5.7)	S ⁵
Magnesium,	130 ± 19	136 ± 26	NS ³	162 ± 23	164 ± 24	NS ²	^{***} 2	^{***} 2	132 ± 22	163 ± 23	^{***} 2
mg 128/ 114	127 (121, 143)	134 (113, 154)	S ⁵	162 (148, 177)	163 (147, 177)	VS ⁴	L ⁴	S ⁴	129 (120, 149)	163 (147, 177)	L ⁴
Zinc (mg)	5.1 ± 0.9	5.1 ± 1.2	NS ²	5.9 ± 0.9	6.3 ± 1.1	^{***} 3	^{***} 2	^{***} 3	5.1 ± 1.0	6.1 ± 1.0	^{***} 2
3.7/ 4.5 ³	4.9 (4.3, 5.4)	5.4 (4.2, 6.0)	M ⁴	5.9 (5.3, 6.5)	6.2 (5.6, 6.9)	VS ⁵	S ⁴	S ⁵	5.0 (4.3, 5.6)	6.0 (5.4, 6.7)	S ⁴
Selenium	17.5 ± 4.5	19.0 ± 5.6	NS ²	20.3 ± 5.5	21.8 ± 5.8	^{***} 3	^{**} 3	NS ³	18.1 ± 4.9	21.0 ± 5.7	^{**} 3
µg	17.5	19.7	S ⁴	19.8	21.0	S ⁵	S ⁵	S ⁵	18.0	20.4	S ⁵
18.3/ 16.3	(13.7, 20.6)	(15.3, 22.0)		(16.6, 23.5)	(18.1, 25.1)				(14.4, 21.0)	(17.1, 24.1)	

L, large effect size; M, medium effect size; NC, non-celiac control group; NS, not significant; S, small effect size; SD, standard deviation; VS, very small effect size. ¹ Recommended nutrient intake calculated as nutrient density per 4.2 MJ for 13-year old girls and boys (NNR 2004).

² Differences between groups analyzed with Independent Samples t-test, *p <0.05, **p<0.01, ***p<0.001. ³ Differences between groups analyzed with Mann-Whitney U-test, *p = <0.05, **p = <0.01, ***p = <0.001. ⁴ Effect size, eta square, ⁵ Effect size, r-value.

Table 5. Completed food frequency questionnaire converted to grams per day and energy percent for 13-years-old (23 girls and 14 boys) with celiac disease (CD) diagnosed in early childhood and a non-celiac control group (NC, 342 girls and 290 boys); Sweden 2006-2007.

Macro	Previously diagnosed (CD)			Non-celiac control group (NC)			CD vs. NC		All		
Nutrients	Mean \pm SD		Girls	Mean \pm SD		Girls			Mean \pm SD		CD
	Median (25 th , 75 th percentile)		vs.	Median (25 th , 75 th percentile)		vs.			Median (25 th , 75 th percentile)		vs.
	Girls N= 23	Boys N= 14	boys	Girls N=342	Boys N= 290	boys	Girls	Boys	CD N= 37	NC N= 632	NC
Fat E% ³	34 \pm 3	32 \pm 5	NS ⁴	30 \pm 4	31 \pm 4	NS ¹	*** ¹	NS ⁴	33 \pm 4	31 \pm 4	*** ⁴
25-35 ⁵	34 (31, 36)	33 (28, 36)	S ⁶	30 (28, 33)	31 (28, 34)	S ²	S ²	VS ²	34 (30, 36)	30 (28, 34)	S ⁶
SFA E% ³	14 \pm 2	14 \pm 2	NS ⁴	14 \pm 3	14 \pm 3	* ⁴	NS ⁴	NS ⁴	14 \pm 2	14 \pm 3	NS ¹
<10 ⁵	14 (13, 16)	14 (13, 15)	S ⁶	14 (12, 15)	14 (12, 16)	S ⁶	VS ²	M ⁶	14 (13, 15)	14 (12, 16)	VS ²
PUFA E% ³	5 \pm 1	5 \pm 1	NS ⁴	5 \pm 3	5 \pm 3	NS ¹	*** ¹	NS ¹	5 \pm 1	5 \pm 3	*** ¹
5-10 ⁵	5 (5, 5)	5 (4, 6)	S ⁶	4 (3, 5)	4 (3, 5)	VS ²	S ²	S ²	5 (4, 5)	4 (3, 5)	S ²
ALA E% ³	0.7 \pm 0.2	0.7 \pm 0.2	NS ⁴	0.5 \pm 0.2	0.5 \pm 0.2	NS ¹	*** ¹	** ¹	0.7 \pm 0.2	0.5 \pm 0.2	*** ¹
1 ⁵	0.7 (0.6, 0.8)	0.7 (0.5, 0.8)	S ⁶	0.5 (0.4, 0.6)	0.5 (0.4, 0.6)	VS ⁶	M ²	S ²	0.7 (0.6, 0.8)	0.5 (0.4, 0.6)	S ²
Fiber	20.0 \pm 5.8	19.0 \pm 9.4	NS ⁴	21.2 \pm 7.91	22.6 \pm 9.21	NS ¹	NS ¹	* ¹	19.6 \pm 7.3	21.9 \pm 8.5	NS ¹
g	21.0	16.6	S ⁶	20.0	20.6	S ²	S ²	S ²	18.9	20.3	S ²
	(15.2, 24.0)	(13.4, 20.7)		(15.5, 24.9)	(16.5, 27.3)				(14.9, 23.3)	(15.9, 25.9)	
Fiber g/MJ	2.1 \pm 0.5	1.7 \pm 0.4	* ⁴	2.4 \pm 0.7	2.2 \pm 0.5	*** ¹	* ¹	** ⁴	2.0 \pm 0.5	2.3 \pm 0.6	** ¹
>2.5 ⁵	2.1 (1.7, 2.4)	1.8 (1.4, 2.1)	L ⁶	2.3 (1.9, 2.7)	2.1 (1.8, 2.5)	S ²	S ²	S ²	1.9 (1.6, 2.3)	2.2 (1.9, 2.6)	S ²

ALA, alpha linolenic acid; CD, group with celiac disease; E% energy percent; g gram, L, large effect size; M, medium effect size; NC, non-celiac control group; NS, not significant; MJ mega Joules; S, small effect size; PUFA poly unsaturated fatty acids, SD, standard deviation; SFA saturated fatty acids VS, very small effect size.

¹Differences between groups analyzed with Mann-Whitney U-test, NS= Not significant, *p < 0.05, **p < 0.01, ***p < 0.001. ² Effect size, r-value.

³E% = percentages of energy in the diet that comes from the energy-giving nutrients. ⁴Differences between groups analyzed with Students' t-test. NS= Not significant, *p < 0.05, **p < 0.01, ***p < 0.001. ⁵Recommended intake of E% according to Nordic Nutrition Recommendations 2004 (NNR 2004).

⁶Effect size, eta square.

Table 6. Intake g/4.2 MJ by food groups for the screening-diagnosed celiac cases, previously diagnosed cases and the non-celiac controls at baseline and follow-up. Presented as median (25th, 75th percentile).

Grain products	Baseline			p-value/effect size			Follow-up			p-value/effect size			
	Screening diagnosed N = 80	Previously diagnosed N = 28	Non-CD baseline N = 619	†	‡	§	Screening diagnosed N = 80	Previously diagnosed N = 28	Non-CD baseline N = 447	†	‡	§	
Bread total	41.0 ¹ [26.3, 54.6]	50.9 [33.6, 79.7]	47.9 [32.4, 66.2]	0.023	0.020 ^a S	0.014 S	41.0 [29.6, 53.8]	61.3 [38.0, 74.0]	46.7 [29.6, 63.6]	0.041	0.009 ^b M	ⁱ NS S	NS ^c VS
Bread low fiber	20.1 [6.4, 32.1]	23.4 [1.7, 41.7]	21.3 [0.0, 41.0]	NS	NS S	NS VS	14.4 [4.6, 24.4]	19.5 [5.4, 46.8]	18.1 [0.0, 39.1]	NS	NS S	NS VS	0.025 S
Bread whole grain	13.3 [0.0, 31.6]	22.0 [4.8, 35.0]	15.7 [0.0, 36.1]	NS	NS S	NS VS	20.1 [8.3, 36.7]	22.0 [2.0, 43.5]	16.0 [0.0, 35.7]	NS	NS VS	NS S	0.021 S
Pastries	8.0 [4.1, 13.1]	3.7 [1.6, 7.8]	6.7 [2.9, 10.4]	0.001	<0.001 M	NS S	1.3 [0.5, 3.0]	1.1 [0.6, 2.5]	6.0 [2.3, 9.9]	<0.001	NS VS	<0.001 M	<0.001 ^d L
Pasta	23.5 [14.4, 36.1]	21.4 [13.5, 25.7]	23.9 [16.2, 38.7]	NS	NS S	NS VS	19.8 [14.5, 33.2]	22.2 [13.5, 27.2]	25.0 [16.6, 37.2]	0.025	NS VS	0.033 S	NS S
Pizza	13.6 [7.7, 20.0]	0.7 [0.0, 17.5]	14.3 [8.6, 20.5]	0.010	0.016 S	NS S	8.7 [1.4, 11.5]	9.2 [0.0, 13.2]	14.7 [9.2, 19.7]	<0.001	NS VS	<0.001 M	<0.001 M
Fish finger	1.6 [0.0, 3.4]	1.0 [0.0, 3.1]	2.1 [0.0, 3.8]	NS	0.042 VS	NS VS	0.0 [0.0, 1.8]	0.0 [0.0, 1.0]	1.8 [0.0, 3.7]	<0.001	NS VS	<0.001 S	0.002 S

CD, celiac disease; NS, non-significant.

[†]Differences analyzed between screened CD, previously diagnosed CD and non-CD with Kruskal-Wallis Test at baseline and follow-up, [‡]Differences between screened CD and previously diagnosed CD groups analyzed with Mann-Whitney U-test. [§]Differences between screened CD and non-CD groups analyzed with Mann-Whitney U-test at baseline and follow-up | Differences between screened CD reported intake from baseline to follow-up analyzed with Wilcoxon Signed Rank Test. ⁱNot significant (NS) p > 0.05. ^aCalculated effect size: VS, very small effect size; S, small effect size; M, medium effect size; L, large effect size.

Table 7. Intake g/4.2 MJ by food groups for the screening-diagnosed celiac cases, previously diagnosed cases and the non-celiac controls at baseline and follow-up. Presented as median (25th, 75th percentile).

Non-grain product	Screening diagnosed N = 80	Baseline Previously diagnosed N = 28	Non-CD baseline N = 619	p-value/effect size			Screening diagnosed N = 80	Follow-up Previously diagnosed N = 28	Non-CD baseline N = 447	p-value/effect size			
				†	‡	§				†	‡	§	
Potatoes	68.2 [48.3, 98.4]	61.9 [47.5, 94.9]	62.3 [39.2, 91.1]	NS	NS S ¶	NS S	75.4 [48.8, 109]	79.8 [44.7, 99.8]	61.3 [39.0, 84.7]	0.005	NS S	0.002 S	NS VS
Fat as spread	4.8 [3.0, 8.7]	10.1 [7.1, 13.3]	6.3 [4.1, 9.6]	<0.001	<0.001 M	0.016 S	5.8 [4.1, 8.3]	8.9 [4.4, 11.6]	6.1 [4.0, 9.3]	NS	0.040 S	NS VS	NS S
Eggs	3.1 [0, 7.5]	3.9 [0.9, 7.9]	3.3 [1.2, 9.1]	NS	NS S	NS VS	3.7 [2.0, 10.3]	3.2 [0.9, 9.8]	3.6 [1.6, 9.1]	NS	NS S	NS VS	0.025 S
Fish & shell fish	9.6 [5.1, 19.2]	7.3 [4.3, 13.3]	10.8 [5.6, 18.8]	NS	NS S	NS VS	10.5 [4.8, 20.2]	6.8 [2.5, 14.3]	14.1 [6.7, 23.3]	0.001	NS S	0.043 S	NS S
Meat total	64.2 [46.0, 85.0]	54.1 [47.6, 79.2]	60.2 [45.3, 81.0]	NS	NS S	NS VS	59.5 [44.3, 79.2]	54.6 [45.3, 72.5]	55.6 [38.4, 74.7]	NS	NS VS	NS S	NS S
Processed Meat	17.5 [10.2, 32.0]	25.7 [14.0, 32.1]	21.6 [13.5, 32.0]	NS	NS S	NS S	27.9 [17.8, 44.2]	25.3 [19.1, 33.8]	25.7 [14.9, 40.1]	NS	NS S	NS VS	0.001 M
Rice	17.6 [8.9, 21.9]	12.2 [6.3, 23.1]	14.5 [6.0, 23.0]	NS	NS S	NS S	19.0 [12.7, 28.8]	22.2 [11.6, 28.0]	17.4 [7.9, 25.3]	NS	NS VS	NS S	0.038 S
Discretionary calories	116 [79.5, 169]	91.8 [60.4, 158]	106 [68.7, 161]	NS	NS S	NS VS	88.2 [55.4, 113]	103 [43.2, 144]	90.6 [58.8, 129]	NS	NS S	NS S	<0.001 M

CD, celiac disease; NS, non-significant; M, medium effect size, S, small effect size, VS, effect size.

†Differences analyzed between screened CD, previously diagnosed CD and non-CD with Kruskal-Wallis Test at baseline and follow-up. ‡Differences between screened CD and previously diagnosed CD groups analyzed with Mann-Whitney U-test. §Differences between screened CD and non-CD groups analyzed with Mann-Whitney U-test at baseline and follow-up. | Differences between screened CD reported intake from baseline to follow-up analyzed with Wilcoxon Signed Rank Test. † Not significant (NS) p > 0.05. ¶ Calculated effect size.

At follow-up, the proportion of eating fish fingers in the screening-diagnosed celiac group and previously diagnosed celiac group was reduced to about 30% in both groups (24 of 80 and 8 of 28 participants respectively). In the non-celiac follow-up control group, 56% reported eating fish fingers.

The proportion that reported eating chicken nuggets decreased in the screening-diagnosed celiac group from 30% to 9% (from 24 participants at baseline to 7 participants at follow-up). In both baseline and follow-up FFQs, one (but different) participant in the previously diagnosed celiac disease reported eating chicken nuggets. The proportion that reported eating chicken nuggets in the two non-celiac disease control groups was almost the same at 27% and 24%, respectively.

Comparisons between the non-celiac disease control groups showed that the follow-up group reported a lower intake of total meat and discretionary calories and a higher intake of vegetables, processed meat, fish, shellfish, and rice than the baseline group.

Everyday life with celiac disease (papers III and IV)

A difference noted between the young women's and young men's understandings of the disease was that the men described more initial awareness of the disease. The young men had all met with someone who had been diagnosed with celiac disease before their own diagnosis and had an idea of what the disease was about. Among the young women, few knew about the disease or knew someone that had the disease before they got their diagnosis.

The analysis of the interviews showed that the experience of the gluten-free food per se was very similar for both young women and men. When they began the gluten-free diet, they were disgusted by it and they described how it took time to get used to the food. Many mentioned that the gluten-free bread was especially hard to get used to and that they had to learn to like it. Even at the time of the interviews, they were continuing to search for improvements in manufactured gluten-free bread. They often used manufactured products but claimed the importance of re-learning to cook and bake in an appropriate way adjusted for gluten-free products. The loss of licorice and finding an acceptable substitute for regular breakfast cereals were battles that many struggled with.

Both the young women and the young men described their mothers as the “engine” of the family who took, at least immediately following the diagnosis,

the role of being responsible for equalizing the old food choices with the new gluten-free treatment. A young man expressed, *“Mom is more familiar, not to say that women and men are different, but it feels like women tend to usually be more familiar with this stuff (gluten-free diet)”*. The fathers were mentioned more often by the young men compared to the narratives from the young women. For both groups, it seemed like the fathers did not have to prove their support by special acts and the young men said that they just knew that their fathers were present and supportive. This interpretation rested on statements made by the interviewed, for example, one of the young men said, *“Dad, did not do anything special, I just knew he was supportive”*.

Both the young women and young men dissociated themselves from being seen as a person who had a life-long chronic disease. They constantly tried to downplay its implications and did not easily talk to friends about the inconvenience they experienced due to the gluten-free diet.

The way they introduced themselves and their diagnosis to others differed between the young women and men. The women said *“I am gluten”*, and the men said *“I have gluten intolerance”*. Most of the young women and men assured that they appreciated knowing that they had celiac disease despite the struggle and worries that came along with the disease and treatment. They were eager to avoid bad health in the future. Further efforts to enhance the nutritional aspects of their diet besides following a gluten-free diet were not prioritized.

Paper III: the young women

An ongoing gendered endeavor in silence, was the main theme that came from the analysis of these four themes; having little margin for personal maneuver, being forced to be responsible, blaming oneself, and struggling with normality. Several sub-themes underpinned these themes, which are summarized below under each theme heading.

Having little margin for personal maneuver

As soon as the young women were diagnosed with celiac disease and were taught about their dietary treatment they ended up under a new paradigm. Food that they ate regularly before suddenly became “wrong,” and health-care personnel tried to persuade them to follow the new diet. A young woman described a situation when a doctor tried to convince her to be compliant to the gluten-free diet by implying that she would become more beautiful: *“I remember the doctor’s reply when I asked what differences I could expect;*

the doctor said that I would gain beautiful hair.... It was as if everything was just positive about this [treatment].”

Their compliance to the new “food rules” was controlled by dietitians and other health-care workers. One intense meeting with a dietitian was described. The dietitian had become aware that the young woman was breaking the food rules, and the young women got a scolding. The young woman indicated that the dietitian was entitled to reprimand her because of her disobedience.

The young women’s personal choices were not only affected by the new food rules. The young women described that their social behavior around food had changed. They felt as if they had become an outsider, as someone who was different in situations related to food. One young woman recalled a situation at school during a practical lesson in home and consumer studies when her teacher told her working group that they should use the gluten-free mix. One boy in the group refused and made a scene in front of the whole class. She felt offended and felt that she was singled out as different.

The young women described various situations where they struggled over their compliance with their treatment. But even if the women experienced a lot of problems when eating away from home they did not stop socializing around food. Different strategies were used in order to cope with the lack of gluten-free alternatives. One young woman described how she used to buy gluten-free food from one place and then joined her friends at the restaurant they had chosen, and there they ate all together. Another strategy was storing gluten-free food at their best friends’ homes. However, the limited food choices often aroused a lot of emotions, such as frustration and aggression that were sometimes directed towards things or people.

Being forced to be responsible

After the young women were diagnosed with celiac disease, they started to see their bodies as vulnerable, and they were warned that by taking responsibility for their food they could affect their health.

In order to be responsible toward their bodies, the young women had to make sure that their food was gluten-free. The risk of being seen as demanding and of “trying to be seen as special” was increased when informing others in advance, which was considered as negative and undesirable. Paradoxically, if the women chose to not inform anyone in advance, they risked being without suitable food and also being seen as irresponsible. This ambivalence could be

discerned when they said that it would be natural to inform others, yet they still avoided telling unless it could be done “in passing.” Being indulgent was the strategy frequently described when no gluten-free alternative was available.

Another way of taking responsibility for having food to eat when away from home was to bring the gluten-free food themselves. This strategy was performed in order to not be seen as a burden, even if it meant an increased workload and was considered as boring. However, this was described as “easiest for everybody.”

Blaming oneself

“Damned if you do, damned if you don’t” expresses quite well the frustration that the young women described that they often had to deal with. If the young women followed the prescribed gluten-free diet, they were considered by the health-care system as eating the right way. If they did not comply with the diet, they, as well as the health-care staff considered themselves as breaking the rules and jeopardizing their health with the forbidden gluten.

When being compliant, if they had to require gluten-free alternatives from others the feeling of being a burden increased. There seemed to be a tendency to interpret others’ actions as resistance towards arranging gluten-free food, which had negative implications for the young women’s self-esteem.

The young women talked in terms of guilt when they expressed that they had something to “confess,” for example, when they told the dietitian that they had cheated and eaten gluten.

Self-blame in food-related situations with friends was often described. For instance, if they went to a restaurant with friends and there was no gluten-free food option, the young women felt as if they betrayed themselves by not being true to themselves and also by leaving their bodies hungry. If this circumstance was discovered by their friends and they were confronted with it, even worse feelings of self-blame occurred. One woman said, *“But then I also feel stupid; if they eat pizza and I am really hungry and I eat a salad, then they suddenly notice ‘Oh, we shouldn’t have gone here’ and then I blame myself because I did not argue for my right; it makes me crazy sometimes.”*

If the young women insisted on going to a specific restaurant, they worried that the others felt obliged to accept their circumstances. This made the women feel bad and awkward for having demanded that the others join them.

Feelings of shame were also described. Situations in which there were few gluten-free alternatives, such as only dry biscuits, and other people had several kinds of cookies and cakes to choose from, could arouse contradictory feelings. Anger and sadness for not having the same alternatives, were interpreted as not being seen as important as the others. The young women also felt shame and guilt for interpreting the situation in such a way, and when considering that their facial expression might have made them seem upset, these feelings were harder to deal with.

The young women described the emotional stress they felt in situations when they were invited to share a meal at a friend's home spontaneously or planned. If the host had forgotten or did not know about their special diet. They felt uncomfortable and feelings of being socially handicapped arose. They also described the awkward feeling of being the one who had to console the hosts and placate their feelings after being exposed as neglectful. They responded to the host by saying it did not matter that the host had forgotten them – although for the women it did matter.

Struggling with “normality”

Most of the young women's families were described as supportive, and they accepted the gluten-free diet as normal. One woman stated that if she never had to leave home, there would be no problem living with celiac disease.

The women were aware of their disease as a life-long condition, but they did not consider it as a hindrance when choosing their future profession. However, regarding their personal and private situation they expressed concern over the risk of their future children inheriting the disease. One young woman expressed a possible situation in which she would not eat the same food as her children. At the same time, she imagined her own mother eating different food, which she concluded was very strange.

Different aspects were considered as being important by the young women when stressing normality in their everyday lives. One woman described that, in order to not be seen as a burden the gluten-free diet was on stand-by at the time she was interviewed. If she became ill later on, she knew what she would have to do, but for now, the benefits of being compliant were not important enough to endure the consequences of complying with the gluten-free diet. For others, the difficulty with the consequences of following the gluten-free diet was a never-ending struggle, even if they had decided to battle it. Another view was described by some of the women who, despite similar narratives to the others about the experienced consequences of living with celiac disease,

said that they had accepted that they had the diagnosis. They refused to let the disease define them and take too much space in their everyday life.

Paper IV: the young men

The main theme, *Conquering the disease and becoming a man* arose from the following three themes: reflecting on the awareness of the diagnosis, being one of the guys, and adjusting life according to the gluten-free diet. Several sub-themes underpinned these themes, which are summarized below under each theme heading.

Reflecting on the awareness of the diagnosis

Various feelings, both positive and negative, were recalled by the young men when they described how they experienced their situation as newly diagnosed with celiac disease. It often seemed like the feelings were tightly connected to their bodies; a negative response to the news led to the feeling of being sick and being unable to go to school. Others recalled that they had finally received an explanation for their increasing tiredness and fatigue (which had previously been attributed to becoming a teenager). When the young men began the dietary treatment, they felt that their strength grew and that they could resume physical activities such as ice-hockey. The news of the diagnosis also raised the hope of being seen as special and getting extra positive attention from others.

Body height was spontaneously mentioned by the young men as something that increased soon after initiating the gluten-free treatment. The hope of an increased body height was also seen as an important incentive for being compliant to the gluten-free diet. One man said, *“Actually I want to eat a gluten-free diet until I’ve finished growing; it is important for me to grow”*.

Some talked about having problems with their stomachs, which was described by some of the young men as being caused by a low fiber intake or an increased level of stress.

The young men had been told by their health-care provider that they should become happier as a positive result of the dietary treatment. The men described that this had been true and they had become happier.

Being one of the guys

The young men considered themselves as being lucky that they were not the only one in the screening study who got the celiac diagnosis at their school. But sharing the same diagnosis did not mean that it was the same as finding support and strength from the others diagnosed. If the others who were diagnosed did not comply with the gluten-free diet, they were seen by some of the young men as unwilling to pay the price of social inconvenience as they themselves did.

Acceptance by their informal group of friends in relation to their diagnosis was expressed as a matter of course by the young men. However, the analysis showed that the shape of acceptance was depending on the position the young man had in his informal group. For example, if the peers of a young man deliberately avoided places where no gluten-free alternatives were served or if the young man with celiac disease could refuse or demand where they should go and eat, the young man was interpreted in the analysis as having a high position in his informal group. One young man stated, *"We never eat at Subway; I resist it. They do have things that are gluten-free but it is extremely boring. So if they are going there, I say 'No, I will not go, you have to go without me.'"*

Another position interpreted as not as strong in the informal group was the position of being allowed to join in when going out to eat. This quote shows another shape of acceptance than the one's described above, *"It can be boring at times, you know, if they do not have anything good at all, or nothing at all. But you can still buy a drink, so it's cool"*.

Not being accepted by peers in the informal group was also described. This was expressed as peers speaking disparagingly about the gluten-free food and teasing, deceiving, and bullying.

Adjusting life according to the gluten-free diet

The young men positioned themselves as being active. The men experienced the choices of gluten-free products as limited, some had begun baking, which led to new knowledge about the gluten-free flour and its baking properties. Other ways of taking action in order to manage their treatment were described as delivering gluten-free alternatives to friends, having meetings with staff from school in order to arrange the best circumstances for the school lunch and the practical home-economic lessons, working for a broader range of

gluten-free alternatives in the school cafeteria, and bringing gluten-free flour to school.

The young men recalled the different ways that their families had responded in a practically manner to the new dietary treatment, and gradually they and their families had learned to accept the new diet. At the time of the interviews, the men thought that the frustration they had felt when beginning the gluten-free diet had been exaggerated. As time went by, they figured that they knew what the gluten-free diet was all about, but there were still some unsolved questions about beer, for example. Was beer an option considering the gluten? How much beer could they consume and who could they ask?

Health seemed to be highly valued, and the young men pointed to the relationship between adherence to the gluten-free diet and avoiding unhealthy consequences. At the time of the interviews, all of the young men expressed that they were dedicated to following the gluten-free treatment. However, some young men described that there had been periods when they had neglected the treatment before. One man described that if he even thought about disobeying the treatment, he felt bad and nauseated, which contributed to strict adherence. Another described how he had felt a strong aversion to gluten after being alerted that he had unknowing consumed food that contained gluten. This notion had led to a need to throw up in order to get rid of the forbidden gluten.

One young man described other negative side effects of being strictly compliant to the gluten-free diet. He described that often when he was invited to social occasions he would not go, he had begun to have problems with trust regarding eating food that others had prepared. The importance of adherence to the strict gluten-free diet was also sometimes hard to interpret. One dietitian had suggested that it was okay to occasionally depart from the strictness of the gluten-free diet and eat gluten.

At the time of the interviews, the young men sought to dissociate themselves from the disease by saying, *“Not that I’m different just because I’m gluten intolerant, it is just that I do not tolerate flour”*. Despite this attitude, the men recalled periods and special occasions that had been hard to deal with. Although friends, teachers, and coaches were described as having a big influence on their treatment, the young men did not seem to confide in them.

Discussion

Main findings

The main findings of this study are that society's gender order has a great impact on how young women and young men diagnosed with celiac disease experience their everyday lives, and that as long as the food intake follow the prescribed gluten-free diet, there is no reason to worry more about the nutrition of adolescents diagnosed with celiac disease than for the nutrition of their non-celiac peers. However, the findings in this thesis also show a need to improve the overall food intake among adolescents, particularly regarding a decrease in saturated fatty acids and an increase of dietary fiber.

The dominant medical system governs the patient

Being seen by the medical gaze

The medical system holds a strong and powerful position in our society. For example, the medical system has the authority to judge an individual as sick or healthy by different investigating methods. A diagnosis of celiac disease indicates that the individual will end up under the medical gaze (34). Most of the young adults in papers III and IV were convinced that they appreciated knowing that they had the diagnosis, but the statement often was followed by "*but....*" meaning that it nevertheless had negative implications for their life. None of the young women in paper III had expected the diagnosis but one woman described how she had started puberty after she had begun the dietary treatment. Another woman did not have to stay home from school because of feeling ill as much as before. Of the young men in paper IV, there were several who described how they had grown more, and had become stronger, less tired and happier after beginning the treatment.

Consequences for food and nutrient intake

Earlier studies have shown some concerns about the gluten-free diet, nutritionally (28, 30, 32, 33), which have caused worries about the long-term health effect of the gluten-free diet. The findings from our study suggest that when counseling patients with celiac disease a special interest should be taken finding gluten-free sources of dietary fiber and in reducing the intake of saturated fatty acids. However, the reported intake from saturated fatty acids

and dietary fiber was comparable by adolescents with celiac disease and the non-celiac control groups, which means that all groups were in need of improving their diet. For parents with children diagnosed with celiac disease, this finding means that as long as the food is gluten-free, they do not have to worry about their children's diet any more than parents with children on a regular diet.

It is, however, important to make clear that papers I and II analyze only the consumption of food and nutrients per day. This is not the same as the amount of nutrients that are being absorbed. Celiac disease is known to affect the absorption of nutrients, if gluten being consumed (116). The bioavailability of a nutrient depends on the interaction between the nutrient and other inhibiting or promoting factors in the diet as well as other individual factors specific to the person who is consuming the diet (32, 117). True nutrient intake takes place when the nutrient arrives at the platform for absorption in the intestine, and this was not studied in this thesis. Caruso et al. (32), showed in their review article that patients newly diagnosed with celiac disease would benefit from supplemental nutrients, because they are at risk of deficiency. They also suggested that annual monitoring of certain vitamins and minerals should be done in celiac patients.

One can assume that food choices are largely altered after being prescribed a gluten-free diet. A diagnosis with a food-related disease could be seen as a turning point as described by Furst et al. which has great implications for food choices (81, 83). Findings from paper II, showed that the screening-diagnosed celiac group changed their intake from baseline to follow-up. In comparison with the other groups, they went from reporting an intake similar to the non-celiac baseline control group to an intake similar to that reported by the previously diagnosed group at follow-up.

In paper II, the findings also showed that the screening-diagnosed group reported a significantly lower intake of bread compared to the previously diagnosed group and the non-celiac control group at baseline. Whether this means that they unconsciously had reduced their intake because they felt it was not good for them or that they had a low intake for other reasons cannot be ascertained by our data. In the follow-up FFQ it was shown that the amount of bread per day on a group level was even further reduced for the screening-diagnosed group. In the interviews in papers III and IV, the young adults expressed how difficult it had been to overcome and learn to accept the food, especially the gluten-free bread. This could explain the reduced intake during at least the first years after diagnosis found in paper II.

The screening-diagnosed adolescents changed their food intake after the diagnosis. In addition to a decreased bread intake, they reported a much lower intake of pizza, pastries, fish fingers, and chicken nuggets. These kinds of food are often seen as non-healthy alternatives. This raises the possibility that some aspects of the gluten-free diet could be considered healthier than a regular diet. However, the decreased intake in these foods was not connected to voluntarily choosing a healthier food. Instead, this suggests that the lack of equal substitutes resulted in the lower intake. When asked about healthy eating during the interviews, the young adults expressed that their main goal was to stay gluten-free, and that it was difficult enough without adding other dietary requirements. Considering that the young adults described themselves as visiting cafés and fast food restaurants rather frequently, dietitians should spend time, discussing how to make healthy choices from the available gluten-free assortment with their patients.

The manufactured gluten-free replacement food products, especially pasta and bread, were commonly used by the groups with celiac disease. Gluten-free pasta for example, was sometimes difficult for the school dining hall staff to make tasty, but if they knew how to cook it correctly it was described as tasty and very similar to gluten-containing pasta. Replacement products that resemble the regular gluten-containing food offered the possibility to emulate the intake of the others and blend in, which is known to be of importance in relationships (68, 89).

Prescribed self-control

The medical health-care system uses different strategies to convince the person diagnosed with celiac disease to follow the prescribed dietary treatment, and examples of what the young adults remember from their contacts with the medical health-care providers are shown in papers III and IV.

In paper III, a young women recounted a situation when the clinical practitioner used the traditional values of female appearance (beautiful hair) to gain attention for the prescribed treatment and, in doing so, asserted what was right for the patient. When using the importance of beautiful hair for a woman, the doctors, as representatives of the dominant medical practice, supported the constructed norms of the importance of being beautiful as a young woman (48). This situation can be seen as an example of the (unconscious) sexual objectification of women. Almost as an expected obligation, women in our society are supposed to try to improve their looks (118). The described narrative can, therefore, be viewed as declaring that the

young woman's appearance at the time was not good enough, which is a message women in general often encounter in their everyday lives. According to Bartky (118), the sexual objectification of women implies that "I must be made to see myself as they see me", which she considers to be a ritual subjugation. Therefore, the situation of the doctor highlighting beautiful hair as an advantage when adopting the gluten-free diet can also be seen as an example of a powerful tool used in order to support self-mediated health-care (36). This finding and the justification to use such arguments should be reflected upon, because we found that the accepted norms of femininity in our society cause a great deal of struggle for young women diagnosed with celiac disease.

The young men recalled that the doctor had told them that they would become happier when they started the new diet. These findings could be reflected on from a perspective of masculinities, in contrast with the above description of beauty and femininity. The promise of being happier for a man supports characteristics such as emotional strength that are compatible with hegemonic masculinity (48). The theory of power that the medical health-care holds can also be used in this situation because the benefits of the treatment will support the self-mediated health (36). Are the differences between how the women and men recalled their meeting with the personnel from the medical system, just a coincidence? Maybe, but none of the young men recalled that they were told that they would gain beautiful hair, and, none of the young women recalled that they would become happier because of the gluten-free treatment.

It was interesting to study how the meetings with the dietitians were described during the interviews. The dietitians informed the patients about different gluten-free foods and products. During a meeting with the dietitian, one of the women confessed that she had neglected the gluten-free diet, which gave the dietitian the opportunity to use the power of the dominant medical system (36). The dietitian took the confession as a reason to reprimand the young woman and used it as a tool to enforce the importance of being compliant. The young woman accepted the rebuke because she had broken the food rules prescribed by the dominant medical system.

Ambiguous messages complicate self-control

A meeting with a dietitian was described by one of the young men in paper IV. The young man had understood the dietitian to give information, contrary the previously described rules for a strict gluten-free diet. The dietitian had meant that it was okay for him to once in a while eat gluten-containing food, but the

young man found this information to be unbelievable. The reason why the dietitian said this or how she actually phrased herself, is not known. This could have been an attempt to downplay the seriousness of the prescribed strictness, by saying that it was not so dangerous to eat gluten occasionally. In order to make the patient feel less confined and restricted by the diet. Although misguided, it might have been based on concerns about the social implication of keeping to the strict diet. Nevertheless, this situation can also be described as an example of when the powerful medical system is ambiguous, which means that the patient is being tossed between somewhat unclear medical perspectives and the knowledge about the importance of following the treatment. As a result, the patient is left with worries and frustration. It seems likely that the patient in such a situation must make up his or her mind about which advice to trust, the previous rules that described a strict gluten-free diet as the only treatment, or the more generous treatment with just decreased gluten content. In practice, this could mean that the patient could reject and disapprove of what the dietitian said and could believe that dietitians are ignorant. Or the patient might approve of the advice and begin to once in a while eat gluten-containing food believing that he is following the gluten-free food rules in accordance with the celiac treatment a decision that most likely will negatively affect the mucosa in the intestine.

The prescribed strictness of the gluten-free diet

Most of the adolescents and young adults reported that they mostly followed the prescribed strict gluten-free diet. In the qualitative work (papers III, IV) the interviews showed that most of the interviewees felt that it was very important to follow the strict gluten-free diet. However, the narratives also showed that compliance to a strict gluten-free diet could shift from time to time. Following a strict gluten-free diet had implications that affected the young adults differently. Some described it simply and said it was very important. One young man described how the fear of unintentionally consuming gluten led to major difficulties for him and contributed to both physical and emotional distress and also to social withdrawal. Another interviewee said that at the time of the interview the gluten-free diet was not a priority and that other things in life were more important.

An important question to address is what is meant by a strict gluten-free diet. A review study by Akobeng et al. (119) claimed that it is “extremely difficult to achieve a diet which is completely devoid of gluten”. A distinction between contamination and occasional transgressions of gluten intake should be made. Contamination of gluten in so-called gluten-free food is an often described problem with a gluten-free diet (27). Catassi and co-workers performed a 90-

days prospective, placebo-controlled, double-blind study on adults diagnosed to celiac disease. The participants were divided into three groups. Each group was instructed to eat a daily capsule containing either 10 mg gluten, 50 mg gluten, or a 50 mg placebo. Before the study began the participants underwent a dietary interview, blood collection for serum anti-tTG anti-body and anti-gliadin antibody measurements, an endoscopy and a biopsy. After the 90 days, each participant repeated the same tests. One patient that had been given a 10-mg capsule of gluten showed symptoms related to celiac disease, but none of the other participants showed significant changes in clinical and serological assessment at this level of intake. However, a daily intake of 50 mg gluten for 90 days was sufficient to reduce the height of the villi in the intestine for several of the participants.

Individual factors are known to affect the safe levels of tolerance to gluten for those diagnosed with celiac disease (27, 119). Biagi et al. (120) calculated that a regular baked bread crumb (about 3 - 4 mm in size) contained about 0,5 mg gluten. This meant, according to Biagi, that inadvertent contamination of gluten-free products is not a major problem, because an individual would have to consume 500 g of gluten-free product contaminated with the amount of gluten found in a bread crumb in order to reach a toxic dose of > 100 ppm gluten. In the paper, the author makes the point that “a sensible and diet-conscious individual” could not by mistake consume that amount. Voluntary transgressions of the diet are different considering that one single regular pasta penne about 4 cm long contains about 209 mg gluten (120).

Sweden and other European countries following the EU commission regulations (Commission regulation [EC] No. 41/2009) must ensure that products labeled *gluten free* do not exceed 20 mg gluten/kg. Specially produced products not exceeding a gluten content above 100 mg/kg are allowed to be labeled *Very low gluten*.

Putting celiac disease and social norms into context

Compliance

Compliance meant the same thing for the young women and young men in papers III and IV, but the consequence of being compliant to the gluten-free diet differed. In Swedish society, normative femininity is represented by being empathetic, and caring and seeing things from the perspective of others (49). These characteristics are not easily compatible with compliance to a strict gluten-free diet because strict compliance requires an attitude of scrutinizing

the given food, demanding special food, and generally not accepting any food offerings from others without questions. This discrepancy seemed to cause a lot of angst for the young women due to the struggle between the expectations of society and the demands of the disease.

The consequences of compliance described by the young men seemed to be heavily influenced by features characterized by hegemonic masculinity. According to Connells theory of gender order (46), a young man's position in his informal group is especially important during adolescence and this finding is in line with the results of paper IV. The young man's position in his informal group had consequences for his possibility to regain man points (which were lost when diagnosed with a chronic disease). By using attributes in accordance with hegemonic masculinity, such as being self-secure, being demanding, and appearing authoritative, the men could strengthen their position. The young men who held the weakest position in their informal group could be, according to Connells theory, described as marginalized. Such a position was described in the interviews. However, under the heading *Compliance* this finding should not be misinterpreted. The ones in the marginalized group were not neglecting the gluten-free diet. Instead, their expense for compliance was higher than for the others and was paid for by being teased, deceived, and bullied by their peers.

The overall reason, for these young women and men to choose and maintain the strict gluten-free diet was that they wanted to avoid future consequences such as diabetes. However, other advantages of being compliant were also described by the young men in paper IV. They talked about their body height, their desire to grow, and the importance of reaching their full potential adult height. One man even doubted that he was going to stick to the gluten-free diet after he had stopped growing. From a gender perspective, this special interest in body height can be seen as a way for men to gain "man points", because men are expected to be tall. This is true for the dominant masculinity in many Western societies (48, 121). Women, according to feminine norms, should be shorter, and even today tall women are being medicalized (122, 123). The young men thought that their increased growth was associated with them being compliant to the gluten-free diet. Some of them had been the shortest in their class prior to the diagnosis, and none of them seemed to relate their growth, to being at an age when boys often begin puberty.

Food as symbols

The gluten-free foods seemed to be loaded with symbols for the young women in paper III. They viewed themselves as different, and they talked about their

dietary treatment as a need for a special diet. They mentioned that their parents had never expected that their daughter would ever be in need of such a special diet. The young women described how they sometimes could feel as an outsider during social meals, because they could not eat the same foods as the others. This finding is in line with Olsson et al. (68) study of adolescents with celiac disease, which showed that the gluten-free food stigmatized them and made them stand out. The young women in paper III interpreted the availability of gluten-free food as a symbol of them being seen and respected. When the gluten-free food was missing, they felt as if they were not important enough to be remembered and that they contributed to extra work for the host. Food as a carrier of symbolic values has been shown earlier in the literature (1, 124). The young men in paper IV seemed to interpret the presence of the gluten-free food somewhat differently than the young women, and they seemed to be less troubled over whether there were gluten-free alternatives or not. Some of the young men dissociated themselves from the gluten-free diet, and stated that the gluten-free food had nothing to do with their identity. This was similar to the finding seen in boys in Williams' study of adolescents with diabetes and asthma, she showed that the adolescent boys in her study made every effort to keep their illness separate from their personality in order to avoid the stigmatizing impact of a chronic disease (125).

The symbolic value captured in the consumption of certain food is often related to status. The interviewed women did not express themselves as if they had a high status in their informal group instead, it was almost as if they made a point of being undemanding in order to not be seen as bossy. During the analysis of the young men in paper IV, it seemed like the young men's position in their informal group was very important for what they could expect and demand in terms of gluten-free choices during a social meal, at least if they did not want to transgress their groups values and social order. If they held a position where they could make demands of special, good-tasting gluten-free food, they did it, without thinking very much about it. If not, their position might offer the opportunity to buy something to drink or eat, but otherwise they ate at home later. For the young men who were in the outskirts of their peer group, the negotiation position about the quality or quantity of the gluten-free food they could demand was at the bottom, which led to withdrawal from social meals. The pattern described above suggests that in situations where young men were in a position to negotiate they did; otherwise, they adapted to their position in their informal group. The young women, on the other hand, seemed to have another relationship with the gluten-free food per se, which was more valued and more closely connected to their identity.

The previously diagnosed group with celiac disease reported at both baseline and follow-up, (paper II), that they ate the largest amount of bread compared to all groups. This is an interesting finding. It seems likely that they could have had a greater awareness of their bread intake, because being on a gluten-free diet means that one must always be on alert, which is a lesson learned from the interviews. Nevertheless, the high bread intake reported by the previously diagnosed group can also be interpreted as a signal showing that it was important to eat bread to symbolize that they were not different; even if they ate gluten-free bread it was still bread. Another explanation could be that the participants in the study were supported by their environment and social context and were served a lot of good tasting gluten-free bread. Another factor could be the age at diagnosis which in previous studies has been shown to have an effect on compliance (126), and although that diet changes takes time to get used to, and appreciation on new foods and tastes.

Taste

Both the young women and the young men in papers III and IV recalled that the specially made gluten-free products had tasted disgusting at first when they began the gluten-free diet, but at the time of the interview, five years later they had become accustomed to the new taste. Another study has shown that when an adolescent thinks that a certain food is disgusting, they will not eat it (87). In papers III and IV, the young adults stated that they did not have any options, and they still had to eat the disgusting food. Therefore, Wiggins's (87), discussion about disgust as a way to define a group, might not fit into a context where an individual eating a gluten-free diet is alone. However, discussing taste and feelings of disgust should be considered if, for example, the medical health-care personnel decides to work with newly diagnosed adolescents in group treatment.

In papers III and IV, the young adults described how they gradually went from experiencing the gluten-free food as disgusting to accepting and even appreciating the gluten-free foods. That pattern is in line with studies that show that one could learn to like the taste of food, because taste is a social and cultural construction (1, 90). It would be interesting to study the kinds of reactions about gluten-free food that a newly celiac-diagnosed adolescent gets from their families, friends and others when they begin with the gluten-free diet. Do they get encouragement, and is their food described as tasty, or is it the opposite? It has been shown that how others express positive, neutral and negative feelings for food is important when approaching a new taste (127). Taste is known to be the primary criterion for making food choice by adolescents (128). Surprisingly, there seem to be rather few scientific articles that have scrutinized the relationship between taste, disgust, and the gluten-

free diet. Smith et al. (76) researched the question “What are the perceived causes that interfere with adherence to gluten-free diet?” In her study 19% (adults) expressed dislike as a reason that affected their adherence.

Alcohol issues

Only the young men in paper IV, raised questions about whether they could consume alcoholic beverages such as beer. They also wanted to know how much beer they could consume and what kind of beer was recommended in order to not exceed the safe level of gluten intake. The young men felt unsure about who they could ask these questions. Questions about alcohol from young adults are important from many perspectives. According to the World Health Organization, alcohol is the third largest disease factor causing millions of death annually worldwide (129). The awareness of alcohol as a negative factor in public health has caused the government in Sweden to give the Swedish National Institute for Public Health the mission to reduce the use of alcoholic beverages. A newly published report shows that norms in society still have a big influence on adolescents drinking behavior (130). However, through strategies, heavy drinking among adolescents has been reduced in recent years. Nevertheless, drinking beer is still connected with a masculine identity in our society and being able to drink a lot (without being addicted) can be seen as important for belonging to hegemonic masculinity (59). During certain circumstances, a man who refrains from using alcohol can be at risk of losing some man points in their masculine capital (52, 131). An explanation for why alcoholic consumption is related to masculinity suggests that men in general are more impulsive and more risk-taking. Under the effect of alcohol, a man would do more risky things (132), and, therefore gain man points. In paper III, none of the young women mentioned alcohol.

How should this issue be approached? Should counseling a young person with celiac disease only concern levels of gluten and should advice be given about gluten-free beer? Or, should such questions be ignored because adolescence and alcohol are seen as a bad combination? Further studies about the meetings between health-care personnel and patients' with celiac disease from the perspective of the patients' starting point should be performed.

Struggling with self-blame

Shame and guilt seemed to be common companions in the young women's everyday lives and strongly connected to food behavior. The women described how they, in relation to themselves and/or others ended up with feelings of

self-blame and guilt in several situations. Earlier studies have also shown that women with celiac disease report these kinds of feelings (61, 73). In the study of young women in this thesis, it seemed as if these feelings should have enhanced the compliance to the gluten-free diet, but the feelings of shame and guilt also seemed costly for the individual, by imposing self-restraint and creating a fear of feeling inconvenient in social situations.

In a recently published study where gender differences in relation to emotional features were studied, it was shown that women tended to be more prone to feel shame, but there were no differences between women and men regard to guilt (133). In our analysis of the interviews in paper IV none of the men expressed feelings of self-blame. This does not mean that they never felt shame or guilt, but they did not express those feelings during the interviews. Our analysis that describes women as more likely to feel shame is supported in Bartky's analysis of women and shame (118). She claims that women are inevitably more exposed to shame because of women's' subordination in the gender order.

Shame is defined as a negative perception of the self, and guilt is defined as a negative perception of one's behavior (133). In order to understand why those feelings of shame and guilt were so pronounced among the women in paper III, it is important to have a broader perspective beyond celiac disease and the gluten-free diet. The dietary treatment should be considered as a turning point for the young women, and, turning points are known to have a great influence in a person's life course (81). Imagine these women as children, as young girls unaware of celiac disease. Assume that they were traditionally raised to at least taste the food that was served, eat the food, speak well about the food and be polite in food situations (1). Then they are diagnosed with celiac disease. They experience the dietary treatment as disgusting, but still they were expected, according to the social norms, to be polite and grateful for the food served. Their condition changed and they must suddenly guard their food intake. They must also accept that they sometimes will end up without something to eat because no gluten-free alternatives are available.

Another explanation for the expressed feelings of self-blame could be that the feeling the young women described was a result of a food conflict (89). Is it possible that the self-blame related to food originally came from an inability to find social approval during the social meal? It has been shown in the literature that the amount of food eaten is reduced when someone joins the table without eating, and that the young women in paper III seemed to experience such situations rather often (89). Does this mean that the self-blame the young women felt can be partially explained by an unresolved food conflict with others around the table?

The young men also experienced a turning point in their life course when they were diagnosed with celiac disease, but their experience of the turning point seemed to provide other consequences than for the young women. One way to understand the differences between how the young women and the young men expressed their situation in papers III and IV, could be to study how the young adults described their families' division of labour. It seemed as if most of the young women and young men came from families that consisted of a mother and a father who had a conventional division of labour. The mothers were described as taking most of the responsibility for the preparation of the gluten-free food, which is in line with previous studies showing that mothers are mostly responsible for serving healthy food (78, 134). Lupton describes femininity as "idealized as being caring and working for others with little thought of oneself" (1). The fathers in the narratives were described as having a quite different role. They were, in a way, described as supportive, but how they provided support was not specifically mentioned. Considering the idea of social learning, when girls learn to be like mothers and boys learn to be like fathers. In this case, that idea suggests that the young women were taught to care about how others perceived the situation and consider the other's needs, and the young men were taught to have a more relaxed position towards food situations.

The importance of social meals

A meal consists of several components and most commonly involves a social dimension, what component will dominate depends on the purpose of the meal and the context. If the meal is constructed in order to meet and socialize, the relationship is superior to the food. If the purpose of the meal is to eat a lunch during lunch break, it might be a chance to combine food and socializing. A popular Swedish TV-show is called "halv åtta hos mig" ("Come dine with me"). Four strangers invite each other to their homes, and each of them cooks and serves a three-course dinner. At the end of the program, the people who have been invited grade the food with points. When watching the TV-show from the couch, it seems as if the food being served is worth more than the company. However, if the host appears friendly and lovely, it seems as if this can compensate for not having an exceptionally tasty dish, which suggests that the hospitality can make the food taste better. Findings from this thesis suggest that it was common among the young women and some of the young men with celiac disease to not have high expectations about the taste of the gluten-free food that was served when they took part in a social meal. It seemed like they did not had the option to value the taste of the food over the relationship, if they wanted to be social during a meal.

In order to not stretch their friendships, the young women declined to take a prominent position when discussing with friends where to go out to eat. Instead of being seen as demanding and requiring gluten-free food, the young women often seemed to choose a backstage position. They expressed that if they participated in the discussion, they risked that their friends would feel forced to go to a place they did not want to go. This behavior can be seen as confusing, when considering how uncomfortable the women were when they did not have something to eat while the others ate. This pattern was not described by the young men. De la Haye and co-authors (135) studied obesity-related behaviors in friendship networks in secondary school students. They showed that fast-food restaurants were not places where young women typically socialized when building networks with friends, which is a behavior in line with findings in paper III. The women described in paper III that their friends often chose cafés or places where they served sandwiches. Gluten-free products rarely were present, or there were not many alternatives available. If the women did not have something to eat, they were unable to behave consistently with the norm in the group, which is known to be important for self-esteem and is a way for women to make a good impression (88, 93). Instead, the women often described that; being without anything to eat made them feel as an outsider and socially handicapped.

De la Haye et al. (135) showed that young men often socialized with their male friends in fast-food restaurants, and that they were significantly alike in their fast food consumption. That finding is in line with the finding in paper IV, which showed that the young men in paper IV, often ended up at fast food restaurants with their peers. Gluten-free food (at least in Sweden) is usually available at such places. The differences in choice of where the young women and the young men went out to eat, suggest a possible explanation to the finding that the women seemed to be much more exposed to being without gluten-free options. The women therefore, had to accept the situation of being without gluten-free alternatives more often if they were to remain social with their female friends, but the men could be social with the male friends and still eat gluten-free food.

Conclusions and implications for future practice and research

After having had the privilege to work with the data in this thesis and also work as a teacher in the training of dietitians I have sometimes felt that, the essence of what it means to work in the medical system, for example, as a dietitian should be discussed in depth. A dietitian working with celiac patients not only should be knowledgeable about gluten-free food, but also should understand how the constructions of norms in a given society affect the patient. Suitable tools are needed to strengthen and support the patient. A subject for future research is to determine how to empower patients to self-mediate their health within their social context.

The first paper showed that the nutrient intake for adolescents on a gluten-free diet was similar to adolescents on a regular diet. This suggests that those who are worried that the gluten-free diet is less healthy than a regular diet should be counseled that it is not. However, there is a need for improving the diet of adolescents in addition to providing guidance about the strict gluten-free diet. The patient should be advised about good sources of dietary fiber and a reduced intake of saturated fatty acids.

The second paper showed that a gluten-free diet had great influence on the diet, causing a change to gluten-free variants of some foods and decreasing the intake of others. The screening-diagnosed celiac group reported a high consumption of manufactured products, which was shown by reporting a similar intake of bread and pasta before and after diagnosis, and a significant reduction in the intake of pastries and pizza. At baseline, the screening-diagnosed group reported an intake similar to the non-celiac control group, and at follow-up, their intake was much more similar to the previously diagnosed group than the non-celiac control group. The findings suggest that a diagnosis of celiac disease represents a major change, and a patient will need support and guidance to manage this change.

The third paper showed that the young women's everyday lives were largely affected by the society gender norms. The characteristics that are favourable for a strict compliance to the gluten-free diet are in opposition to expected features of femininity, such as caring, being empathetic, and seeing things from others' perspectives. Circumstances related to the adherence of the gluten-free treatment caused shame and guilt for the women. The findings suggest that health-care personnel need to review how they work with young women diagnosed with celiac disease, which is a subject that needs to be investigated in the future. The results also showed that a woman with a celiac

disease needs to be empowered in order to improve the self-monitoring health of her health.

The fourth paper showed that young men's experiences of living with celiac disease were in accordance in how they were accepted in their informal group. Despite the negative aspects of being a man diagnosed with a chronic diseases such as celiac disease, there seemed to be, to some extent, ways to compensate for the non-masculine value of a chronic disease. By being in a position in their informal group where they could strive for the characteristics recognized in the socially constructed norm of the dominant masculinities, "man points" could be obtained that also worked in favor of being adherent to the gluten-free diet. However, not everybody wanted to or was in a position to achieving enough "man points" and those men are not heard in the medical scientific world today. The findings offered new insight how young men experience living with celiac disease that has not been shown before in the scientific literature.

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