

Living with Celiac Disease: Norms of Femininity and the Complications of Everyday Life

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Abstract Women with celiac disease are often described as being exposed to negative emotions and experiences related to the treatment of celiac disease, the gluten-free diet. To explore the daily consequences of diagnosis and their daily experiences of living with celiac disease, interviews were conducted with seven Swedish young women who had been diagnosed with celiac disease by screening in early adolescence. The semi-structured interview transcripts were content analysed using a gender perspective. The analysis showed that these young women's daily experiences were coloured by the conjunction of their dietary treatment, their social relationships, and social norms. This means that recurrent food situations often clash with the normative constructions of femininity and social norms of eating with an adverse effect on dietary compliance.

Keywords: adherence/compliance, gluten-free diet, gender, young adults

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1. Introduction

Medical research describes celiac disease (CD) as a common food-related disease, more frequently diagnosed among women than men [1,2]. The only treatment of CD is life-long exclusion of gluten from the diet; a protein complex found in wheat, rye and barley [3]. Although a gluten-free diet (GFD) often brings improved health to the patient, the lifelong adherence *per se* has been associated with negative effects such as perceptions of the specially-produced gluten-free products, the on-going risk of gluten exposure and difficulties with routine commensality [4,5,6]. Roos et al. reported that Swedish women with CD in remission use health care more frequently in women in general [7] and that their whole life was affected by having a chronic disease [8]. Earlier studies had shown that diagnosed women around 50 years old experienced CD as a greater burden in life compared with their male counterparts [6,9]. One previous study made an attempt to explain why women especially are affected by CD: it has been suggested that women's dual responsibility for household and paid work could be even more pronounced when a GFD is required, resulting in a triple burden [10]. The present study seeks to broaden our understanding of the way that gender influences experiences of CD.

Being a woman in a Western society implies a framework of norms concerning how women are expected to act, behave and look [11,12]. From a gender perspective,

those norms are seen as being socially constructed, dynamic, and resting on the notion that different gender norms are formed in relation to circumstances such as sex, culture, economy, power and history [13]. In daily life, various femininities and masculinities are constantly re-constructed in various ways in relation to how gender shall be performed and how various gender constructions relates to social structures (i.e., a gender order, visualized in social practice as labour, power and personal relationships) [12,14,15]. In Western societies, masculine attributes are generally more valued than feminine, and some masculine attributes are more valued than others; forming the so-called 'hegemonic masculinity'. Also, among women, some female attributes are more highly valued, and Connell calls this the 'emphasized (normative) femininity' [11].

Social norms are known to affect food intake [16,17]. Studies have reported difficulties for patients following a strict GFD when their treatment clashes with the social norms of eating [6,18]. Sverker and co-workers reported that patients with CD felt embarrassed when requiring different food, not being taken seriously by staff in restaurants, being forgotten, or being given unwanted visibility when their specific food intolerance became a focus of attention for others [19]. Social meals are also known as an investment to improve relationships; by matching one's own food intake with others the relationship is facilitated [16,20,21]. CD patients are known in the literature for their expressed feelings of being different in food related situations [22]. Food choice conflicts may arise in situations when an individual

following GFD is offered a choice of gluten-free food very different to that of others at a social meal occasion, or when no gluten-free options are available [8,19]. Jacobsson et al. showed that women with CD could jeopardize their strict treatment in order ‘to not stand out from the crowd’ [23]. Studies have also shown that women with CD, regardless adherence to GFD, report higher psychosocial distress than women without CD [24,25].

Furthermore, in terms of the broader context, medicine and medical staff have a high status position in society and strive to normalize what is seen as not normal in different ways [26]. Holmes and Gastaldo used the terms ‘pastoral’ and ‘disciplinary’ power to describe the ways the relationship between patients and medical staff can be understood [26]. The use of pastoral power suggest that medical staff try to build a close relationship with the patient so that they can influence thinking and behavior using patient emotions in order to improve adherence to prescribed treatment. Disciplinary power is an authoritative form of influence implying that medical staff tell patients what they should do.

In this paper we aim to study the experiences of the everyday life among Swedish young female patients who were diagnosed with CD through a screening study. To enhance compliance with the necessarily strict dietary treatment necessary, it is arguably important to consider patients’ lives from different perspectives. By analysing those narratives from a gender perspective, we seek to show how gender norms influence their lives as people with CD.

2. Method

2.1. Participants and Procedures

The young women had all been diagnosed with CD through the first phase of a Swedish school based screening study entitled Exploring the Iceberg of Celiacs in Sweden (ETICS). Five years after their initial diagnosis, nine young women aged 17-18 years from different parts of the country, were sent a letter of invitation to the present study, and a few days after, the first author (EK) telephoned the participants and asked if they wanted to join the study. Two participants declined invitation; one was not interested and the other was not available during the period when the interviews were planned, resulting in seven participants. The ETICS-study had been undertaken in 2005-2006 in five geographically dispersed municipalities involving children in the 6th grade of school i.e. 12-13 years of age. The screening study is described in detail

elsewhere [27]. Requirements for participation in the present study were: being screened for CD in the ETICS-study; being female, being born in 1993 and still living in the same area as at the time of the screening. All current participants were Swedish speaking and attended upper secondary high school. All but one lived with their families. They were offered two cinema vouchers as thanks for participation. Before the interview, and before giving written consent, the young women were reminded about their rights, and that the content of the interview would be handled confidentially. This study was approved by the Research Ethics Committee of Umeå (Dnr 2010-110-31 M).

2.2. Data Collection

Participating young women chose where the interview took place and mostly this was in a school environment, library or cafeteria. Interview content was based on the guide developed by four of the co-authors. The first author conducted each semi-structured interview which lasted about 1 hour and was audio-recorded. The interviewer aimed for a relaxed and friendly atmosphere to make each participant feel comfortable. The interviews started with the prompt: ‘Tell me what it is like to live with CD’. There were also questions about their experience of being screened, dietary changes, and ways that CD affected their social life, health and perspectives on the future. All the interviews were conducted in Swedish and the authors translated the citations used in this article to English with help of an English-speaking language reviewer.

2.3. Analysis

Data analysis followed the content analysis procedures detailed by Graneheim and Lundman [28]. Immediately after each interview, the audio-recording was listened to and descriptive notes were written. Thereafter, the first author transcribed all interviews verbatim and four of the authors read the transcripts repeatedly during analysis. The starting point was a manifest inductive analysis. During the analytical process the first author formulated the initial meaning units and codes, and then all the authors discussed the continued analysis step by step to formulate categories and sub-categories (Table 1).

The underlying meanings throughout the meaning units, codes, categories and sub-themes were discussed and reflected on by the authors during several meetings resulting in four formulated themes with several sub-themes (Table 2). The formulated themes were further considered from a gender perspective resulting in one main latent theme.

Table 1. Examples of meaning units, code and category from participant narratives

Meaning units	Code	Category
It feels as if I am troublesome, not like one of the crowd.	trouble outsider	Feel different
A person like me, one does not take into account.	outsider	
I still feel that it is difficult to have CD, and that they may think “she should not be here.” It becomes such a hassle.	outsider	

Table 2. Experience of daily life for young women with celiac disease illustrated by sub-themes, themes and a main theme

Main theme	A tacit gendered endeavor			
Theme	Having little margin for personal manoeuvre	Being forced to take responsibility	Blaming oneself	Struggling with 'normality'
Sub-theme	Being ruled by the health care system	Being aware of short and long-term complications	Exposing the body to forbidden food	Adjusting to new rules
	Feeling aversion to gluten-free products	Acting proactively	Not asserting oneself	Keeping a low profile
	Feeling an outsider in food-related situations	Preventing relational conflicts		Stressing the normal

2.4. Trustworthiness

It is essential that trustworthiness is reinforced during the whole research project from gathering data, the analytical process and into the writing [28]. The credibility was enhanced by the selection and utilization of citations from the interviews. Strengths of the present study are that participants of the same age were interviewed, living in different parts of the country, knowing that they all had experiences of being diagnosed with CD about five years earlier, giving very similar durations and socio-medical contexts. The small sample, only seven interviews, can be seen as insufficient, but the participants shared their experience with an engagement providing a robust set of material. Four of the authors read all the interviews and considered them as rich and comprehensive. The analytical process with codes, categories and themes on different levels was strengthened by the joint work of the authors. During the analysis we tried to be as close as possible to the text. Within the group the authors had knowledge and expertise from earlier gender studies, qualitative research methods as well as research and clinical work with CD patients. A wide range of competences and professions was represented in the research group; registered dietitians, registered nurse, pediatrician and a sociologist. Throughout the whole working process several discussions and reflections pervaded the research process to minimize the impact of our preconceptions of the topic which also is an important dimension of trustworthiness (dependability). Although the results are inevitably located in a specific social and cultural context, the gender and age dimensions of this study - young women – offer the prospect of application to other patients where medical treatment includes dietary restrictions.

3. Findings

The four themes derived from analysis were: having little margin for personal manoeuvre; being forced to take responsibility, blaming oneself and struggling with 'normality' (Table 2). These themes were each underpinned by several sub-themes. Findings are presented using the themes and sub-themes illustrated with text from the transcripts. After the formulated themes were considered, the analysis from a gender perspective resulted in one main latent theme: a tacit gendered endeavor.

3.1. Having Little Margin for Personal Manoeuvre

3.1.1. Being Ruled by the Health Care System

It had been with great astonishment that these young women received their CD diagnosis through participation in the celiac screening and after the diagnosis they were offered contact with health-care service. During meetings with medical-staff they were informed about the disease and the need for a lifelong GFD. The prescribed treatment left no room for occasional transgressions, which meant that they were told that, if they deviated from the strict diet, they would be "doing wrong". One woman described how the doctor tried to convince her to be GFD compliant by stating that her appearance would improve because of the treatment, implying that her appearance at the time was not good enough:

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 [the treatment]. *Participant 6*

At the time of the interviews the young women were still 'controlled' by the health care system. One woman had recently had a meeting with a dietitian and had confessed disobedience in relation to the treatment. The dietitian replied by scolding the woman, telling her that she would cause damage to her own body. The young woman said that she believed that the dietitian was entitled to reprimand her as she had transgressed the 'food rules'.

3.1.2. Feeling Aversion to Gluten-free Products

The young women described how they had felt sadness and anger when they had realized that they could not continue to eat their gluten-containing favorite bread, biscuits, candies and so on after starting the GFD. Even now, they seemed to still reconstruct the view of gluten-containing food as being more attractive both in taste and appearance than gluten-free food.

The introduction of the GFD was described as challenging and their first impression was that it was disgusting.

Really disgusting! Especially the bread ... and the pasta! I really don't know what to call it. *Participant 3*

3.1.3. Feeling an Outsider in Food-Related Situations

Away from home all the women talked in terms of 'self and the others', symbolizing themselves as being the ones

that were different in food related situations. They confided that there had been situations when the GFD had made them feel embarrassed and stigmatized.

I think this is almost the worst feeling, it sounds awful but it's like being a bit socially handicapped.

Participant 5

Feelings of being an outsider were recounted for many situations at school when food was involved. One described a difficult situation, ironically during a practical lesson in home and consumer studies. The teacher had told her small kitchen group that they should use the gluten-free mix, instead of regular flour, but one of the boys in the group refused and made a scene in front of the whole class. The young woman had felt offended; as if she was singled out as deviant by virtue of the food she had to eat.

3.2. Being Forced to Take Responsibility

3.2.1. Being Aware of Short and Long Term Complications

After screening, the young women reconsidered their bodies as vulnerable and so they felt responsible for their health especially with regard to food. After having started the GFD some women experienced short-term complications such as stomach ache if they ate gluten and an overwhelming fatigue if they ate it for several days.

However, they reported that they would still have joined the screening study even today, despite the difficulties they had encountered with the GFD. One stated that she preferred knowing as much as possible, even though the diagnosis had made her life more difficult and her present situation was far from ideal. She was concerned about the risk of developing serious diseases as a result of not following the GFD.

Yes, absolutely...even though it sucks now and I would have managed just fine without me knowing about it...

Usually, it leads to consequences if you have celiac disease and eat gluten...and I do not want that. So, I had absolutely joined in. *Participant 6*

3.2.2. Acting Proactively

Participants saw it as their responsibility (or possibly their mother's) to inform others about their need for a GFD before a meeting or visit. When telling others, they felt that they could share some of the responsibility for the forthcoming meal. Informing others in advance could also made them feel socially uncomfortable and they felt it increased the risk of "trying to be seen as special" in an unfavorable way, or being seen as demanding which was also considered undesirable. An ambivalence could be discerned when they said that it would be natural to inform others, and yet still avoided this unless it could be done 'in passing'. If the women chose to not inform in advance they risked being without suitable food and also being seen as, paradoxically, irresponsible or at least thoughtless.

Then I have to tell [need for GFD]. It's just my own fault if they say, "but why have not you said anything?"

Why haven't I done it? Because I'm stupid. *Participant 4*

One strategy they used to guarantee gluten-free food was to bring food themselves when going on a visit. This

was perceived as being boring and increasing their workload. At the same time, it was described as the "easiest for everybody" by the young women. One of them explained how she bought gluten-free food from a nearby cafeteria and then joined her friends at the restaurant they had chosen, and there they all ate together.

When eating out, I run into the Mekka [a cafeteria that serves gluten-free bread] and buy a gluten-free sandwich and then I go back into the Subway and share the meal with them. *Participant 7*

Storing gluten-free food at their best friends' homes was also a strategy used in order to always have something to eat when they visited.

3.2.3. Preventing Relational Conflicts

The young women felt they were carrying the overall emotional responsibility for eating occasions and therefore they wanted to be seen as flexible. They knew that they could use their diagnosis as a tool to get their way when discussing with their friends where to eat. Lack of gluten-free food was considered a strong argument when negotiating with friends which restaurant to choose, because it often seemed to override other people's suggestions. If they insisted on going to a specific restaurant they were worried that others would feel obliged to accept their circumstances. The women deliberately chose a 'backstage' position, rather than being more actively involved.

If no gluten-free options were available at a social gathering, the young women reported that they became somewhat distressed because they had been forgotten, but also tried to demonstrate understanding by saying that anyone could forget.

The hardest [thing] is when [deciding] to eat anywhere. If I am invited for refreshments for a birthday snack, and I have to notify in advance 'I'm gluten' only remember it, then I feel so stupid, also thus if they forget it, then I feel stupid because they feel stupid because they have forgotten about it, because it's not so easy to remember. *Participant 7*

One woman narrated that initially she had made a serious attempt to be strictly gluten-free, asserting the GFD as her first choice.

I was totally... I really went all in [with the GFD] ...No, not a bit wrong, and we did go to one of these... dieticians? And so we talked... It's pretty amazing. So, that was me, it was a whole year there, the entire seventh grade, so to speak. I was completely free of gluten. *Participant 6*

She described how she had then been questioned by a near relative for being too strict on herself, especially when they were abroad.

Many times when we were travelling she said, "You can cheat a little bit [by eating the gluten]. You have to taste this; this is the only place you can eat this." You can cheat a little' *Participant 6*

The young woman had considered an explanation for that attitude; she believed that her ambition of strict GFD compliance had negatively affected the other person's feelings. She had eventually gone back to a normal, gluten-containing diet, but said in the interview that she might consider becoming stricter again if she moved and lived by herself.

Occasions when the young women were invited to share meals at friends' homes spontaneously or as a planned visit, could be challenging. They found it emotionally difficult to handle if the host had not realized that they could not eat like everyone else, or if the host knew of their special food requirements but had forgotten to prepare something suitable. At such moments, they felt very uncomfortable in the situation, those negative feelings related to the inconvenience they caused, and the risk of being seen as troublesome by causing extra work for the host. One described the awkward feeling of having to console their hosts in such situations.

It has happened a few times that they've forgotten about it, they have prepared and cooked the (gluten-containing) food and then they feel a little bit stupid, you know... And then... [the young women would reply to the host]... "No, but it doesn't matter"... But it does anyway, you know? ... You know what I mean?

Participant 1

In order to simultaneously take care of the shortcomings of others and to not be seen as a burden, the women adopted a general principle that 'there tends to be at least something I can eat'. This attitude meant that they believed that there would probably be some gluten-free alternative available to eat or at least something to drink. They learned not to have high expectations when it came to food issues and to be self-sacrificing, or at least to play that role to ease social difficulties.

3.3. Blaming Oneself

3.3.1. Exposing the Body to Forbidden Food

After they had been prescribed GFD they learnt new perspectives on right and wrong for eating. If they did not follow the prescribed food rules they felt bad for breaking those rules and for exposing their bodies to the forbidden gluten. At the time of the interviews, all the women had at least occasionally, consciously or unconsciously, eaten gluten. One woman recalled that after once having satisfied her immediate needs for the desired taste of gluten-containing items, awareness of the risk of hurting her body made her feel bad about herself.

You always end up with a bad conscience... I don't like it when you harm the body like that... it makes me feel bad. *Participant 1*

Even if they clearly felt that they were not to blame for having the disease, they stressed their obligation to make decisions about eating gluten-free food in every food choice situation. If they consciously ate gluten they expressed it as cheating; implying that they had something to confess.

3.3.2. Not Asserting Oneself

Adhering to the food rules and avoiding gluten was also described as an act that could cause emotional distress. They blamed themselves instead of their friends when they were going out to eat with friends and ended up at a place where no, or very few, gluten-free alternatives were served. One described a situation when she and her friends visited a restaurant and she was really hungry. The only gluten-free alternative she could order was a simple salad and after eating for a while, her friends realized her

situation, and pitied her for not having any 'real food to eat'. The woman blamed herself for not having argued for another restaurant and felt embarrassed when she suddenly was confronted by her friends. This ended up in complex feelings of self-blame.

But then I also feel stupid; if they had 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. *Participant 7*

Organized eating occasions where GFD could be ordered (and paid for) in advance were profoundly frustrating when the arrangements did not work out. Such an incident was recounted by one woman at a feast organized by the Swedish church to celebrate confirmation for her and some other youngsters. An abundance of gluten containing cakes and pastries were on offer but only one kind of gluten-free everyday plain biscuits were served. This event influenced the woman in various ways. She was sad that she did not get similar bakery products as the others but was, at the same time, angry that the caterers had not made more of an effort on her behalf as she and her family had paid as much as the others. Paradoxically, she was also ashamed that her facial expression when she understood that only plain biscuits were available for her might have made her seem spoiled. Another woman described that after having been in situations where she had to make decisions about eating gluten or not she had noticed that her mood was affected.

I was so annoyed and I took that anger out on everything else because I felt very restricted at certain times. *Participant 5*

3.4. Struggling with 'Normality'

3.4.1. Adjusting to New Rules

Despite negative first impression of the GFD as disgusting, these young women mostly adjusted to the new taste. At the time of the interviews, they had learnt to accept, and they often appreciated the gluten-free alternatives.

The food may not always be as good, but you can bake and then it [the bread] will be delicious ... but it takes time to adapt. *Participant 2*

Lack of gluten-free alternatives was still troublesome when wanting to share meals away from home, or when ordering takeaway food. However, even if they experienced a lot of problems when eating away from home they did not stop socializing around food.

I do not want to prevent you (friends) from going and eat there (restaurant). If you want to eat ... we eat there ... then we can see if I can eat something else or I eat somewhere else then. *Participant 4*

Home was described as a sanctuary, where the women felt they could relax from being on guard about their food intake. One said that if she never left home there would be no problem living with CD. The women were aware that their treatment caused more work for their mothers, but seemed to accept it as natural. This was very different from how they felt about the increased workload for persons outside the family, where they mostly felt they were a burden.

But at home, you are not seen as a problem. So it's very good. *Participant 7*

Such comfortable attitudes towards home seem to have developed because of their mothers' efforts. Initially, practical support such as learning about baking, cooking and buying gluten-free food was provided mostly by their mothers. The women interpreted their mothers' supportive behavior as an act of trying to balance the new food rules with the old ones to lower the threshold of the transition to the GFD. However, one woman reported that since her mother was not interested in cooking and baking the mother had experienced a tough time to cook GFD. The fathers were only mentioned briefly and mostly described as not taking much active part in their gluten-free treatment. They seemed to accept their fathers' attitudes.

3.4.2. Keeping a Low Profile

Keeping a low profile was generally expressed in terms of not wanting to appear as someone having a disease. The women wanted to be seen as everyone else and disliked being pitied or treated as victims and pitied.

I think it's a bit hard to be treated as: "Oh No, poor XXX ... what a pity it is for her". I have always thought that that is hard. *Participant 5*

They responded to general questions about how they experienced living with CD by playing down its implications. In accordance with this, they used the strategy of waiting as long as possible before they mentioned their need for a GFD to new acquaintances. The women mostly kept quiet about their personal troubles and concerns about their dietary treatment, such as feelings of restriction, self-blame, guilt, shame, and worries. Only few had spoken to anyone about those feelings.

Mothers were sometimes mentioned as a potential conversation partner. At time of the interviews, the women stated that they had become used to not speaking about their feelings concerning the disease and instead they had learned to be pragmatic and adapt to everyday situations.

I have not really talked about it ... I mean talk ... talk with anyone ... I think. Maybe with my best friend, but I do not think so...it must have been long ago, in that case. *Participant 5*

When they spoke about their disease they often used the expression 'I am gluten', as an abbreviation for 'I am gluten intolerant'. Their experience was that few understood the term 'celiac disease'. The phrase 'I am gluten' was commonly used as a way of explaining their limited opportunities regarding food and as a reminder to others not to forget about their special diet.

3.4.3. Stressing the Normal

These young women had different ways of stressing the normality of everyday life with a diagnosis of CD. Overall, the women did not believe that their diagnosis would affect their choices of careers in the future. They believed that they would be able to choose their profession as freely as their friends. Regarding their private sphere they wondered how it would be running a family of their own, considering the food situation and preparing different dishes with different content. They also considered the hereditary possibilities, and were concerned when thinking of that aspect of the future.

I wonder if my children will inherit it and how it will be later. *Participant 3*

Not all the women had taken a stand on being strictly gluten-free; one was ignoring the dietary treatment and chose to eat gluten-containing food instead of dealing with the social difficulties of following a GFD.

Probably there was some reason that I stopped eating right [GFD] for every time I went away, not to my friends, but acquaintances it was always "X this is your food." "Oh no, you need GFD, and we have forgotten it. We're so sorry; we'll run to the store and buy new food." ... It feels like they had to change everything for my sake. *Participant 6*

Another reported that only on special occasions they would relax the rules of GFD and eat what was served in order to blend in. There were descriptions of enduring those difficulties that the diagnosis caused and accepting the struggles as something unavoidable. There were also women who had taken a different stand and had decided to not let the disease define them. Instead they wanted to take control over their situation by accepting CD as an unavoidable feature but not give it too much space in their lives. One explained that this stand also had implications for the people around her. They had to accept her as someone having CD and they also had to make their own adjustments to keep the relationship working.

I do not think that gluten intolerance, being celiac, defines me. It is beyond me, it's a thing that I have. Like all have two legs and two arms and so on. I try to not let it define me. *Participant 5*

4. Discussion

Analysis of the interviews showed that living with celiac disease for those women was mainly a tacit gendered endeavor. When struggling with adherence to their dietary treatment, the young women always had to conform in food related situations. Reflecting upon their narratives from Connell's perspective of gender [13], analysis showed that the expected norms of femininity such as moderation and caution often came in conflict with their strict dietary restrictions. The traditional femininity snared them and hindered them from claiming their right to GFD in different situations; instead they received training in adaption and reinforced the norms of femininity. However, one of the young women chose not to follow a GFD at all. Her choice of path could be interpreted as an active lifestyle choice, but can also be seen as a choice not to be challenged in her way of constructing her femininity. Ambjörnsson, showed in her study of upper secondary high-school girls in Sweden that the expected norms of femininity for belonging to the 'good' girls included moderation, control, self-discipline, care, caution, empathy and to adjust to predominant social norms such as, in their case, to remove most of their hirsuteness on a near-daily basis [29]. Our study showed that the treatment of CD is not easily compatible with the expected gendered and social norms of being a young woman in our society. In contrast, we have previously shown that norms known for their masculine features as being demanding and self-assured seems to be more compatible with strict adherence to GFD [30]. We argue,

after having analyzed the narratives in this study, that being strictly compliant with the prescribed diet for CD is affected by socially gendered norms.

4.1. Having Little Margin for Personal Manoeuvre

When these young women had first received the screening results and were diagnosed with CD, they felt that their personal room for manoeuvre was limited. They recalled situations showing how they experienced the encounter with the health care system, and how they became a target for medical care. To our knowledge there are no studies on how preconceptions of the diagnosis CD, gendered expectations and personal values among medical staff, affect interaction with the diagnosed patient and this was not the aim of this study either. In the present study, a situation was recounted where the clinical practitioner used 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 stressing the importance of a beautiful hair for a woman, the doctor, as representatives for medical practice, supported the constructed norms of beauty as the importance of being a woman. Bartky argued that women seem to be under an obligation to try to improve their looks [31], therefore the doctor's focus on the patient's hair could be seen as an example of the (unconscious) sexual objectification of women. The promise of beautiful hair when following the treatment could also be seen as an act of trying to impose a discourse of self-mediated health, probably foremost for women but also an example of how the medical system governs through guiding by use of what has been termed pastoral power [26]. Another form of power that medical practice upholds was also evident in the narrative of a young woman's meeting with the dietitian. During this meeting the young woman gave the dietitian the right to reprimand her which could be seen as an example of how medical system use disciplinary power in order to govern the patient [26].

Another way that young women experienced a reduction of their personal influence was the treatment with strict GFD itself. Young women in our study described how they first found the GFD disgusting and also how they gradually accepted the food. What do we mean by acceptance? From a medical perspective, acceptance is often measured by the relationship between the prescribed treatment and how well a person acts in order to gain positive health outcomes. However, acceptance does not necessarily have to be favorable for the health outcomes outlined by the treatment; it could also mean an acceptance of the diagnosis but choosing not to comply with the treatment as was the case with one of the young girls in our study did [32]. Other concerns in her life had higher priority than following the gluten-free diet. Previous studies have shown that health-care providers do not always succeed in communicating information about a chronic disease so that the patient's potential for following the prescribed treatment will be strengthened [4,6].

After diagnosis, the women experienced a feeling of being an outsider in food-related situations. In Sweden, the social norms applying to food situations are still

primarily to be able to eat everything served. Our analysis showed that gluten-free products in itself carried for those women, beside nutritious aspects, also a value of proof, when offered, they knew they were known, accepted and respected by others. Being without a gluten-free alternative, which was commonly recalled, created insecurity and also seemed to work as a reminder for the women to be flexible in order to deal with the occasion. Feelings of being different caused by eating differently from others are well-known features of living with CD [5,18].

4.2. Being Forced to Take Responsibility

Participants described how they felt responsible in every food situation they encountered. The responsibility was not only about their adherence to the dietary treatment, but also related to how others perceived their special need for a strict GFD. As a coping strategy, these young women generally adopted an attitude of being indulgent instead of being rebellious if GFD was unavailable at social gatherings. This concern over other's well-being could be seen as attuned with the normative femininity described by Ambjörnsson [29]. She suggests that the norm is that women are expected to pay attention to, and be sensitive towards, the personal feelings of others.

The young women's sense of responsibility could also be seen as a balance between maintaining good health and maintaining positive relationships. The women in our study tried to take responsibility, by constructing and reconstructing the discourse of being an ordinary woman. According to Skeggs, subordinate groups – such as the lower socio-economic group in that study and those unable to eat the “normal” food here - have to continuously prove their respectability by being as ordinary as possible [33], while those who are able to eat ‘normal’ food do not need to prove their respectability in food situations.

4.3. Blaming Oneself

In the present study, the young women's narratives disclosed their empathy for others often resulted in feelings of self-blame, i.e., shame and feeling guilty. The concepts of shame and guilt are often used synonymously, but the concepts can be seen as distinct from each other [34]. Shame is described as a negative perception of the self, while guilt is described as a negative perception of one's behavior [35]. Feelings of shame and guilt have previously been reported as features of living with CD [19], but, to our knowledge, have not been explored in depth. In our study the decision to strictly adhere to GFD could result in emotional conflict framed by self-blame. For example, avoidance of demands about which restaurant to visit for fear of being seen as troublesome in social situations.

In an attempt to understand the feelings of shame and guilt expressed by these women it is worth considering their socialization as younger children before the celiac screening; their pre-celiac period. At that time, they ate and drank without thinking, or even knowing about gluten. We can assume they were more or less socialized to traditional table manners with the expectations that they

should eat the food that is served, to at least taste the food, to eat up, to be polite, and to speak well about the food [15]. Later, after their CD diagnosis, they reported that they must eat food they disliked (at least sometimes), and even show some gratitude. They also, had to be on guard about food content, and accept that, now and then, they would probably be without anything to eat. At the time of the interviews, when the women looked back, they remembered that pre-celiac period as unproblematic regarding food and eating. As a note of caution, though, other studies have shown that food is not unproblematic for children in general [36,37], and it is possible that the young women's memories were colored by their later experiences of living with CD.

Shame causes a person to withdraw, and while withdrawal could work as a protection against being hurt, but could also be self-destructive [38]. Considering the fact that the women in our study generally kept quiet about their feelings of self-blame, shame and guilt, health care providers should be far more alert to this undertow. It is worth noting that, regardless of adherence to the GFD, a previous study showed that women diagnosed with CD seek more health care than women in the general population [7], and both men and women with CD are grappling with many psychological difficulties [6,25,39,40].

4.4. Struggling with 'Normality'

The discourse of normality was narrated by the young women, and struggling to 'be normal' seemed to be an enduring issue in their lives. They found no reason to speak about their diagnosis unless food was involved. Equally, they rarely spoke about the troubles they encountered in relation to food, in order to not be seen as deviant and so they did not have to deal with others people's pity. Such behavior could be seen as understandable in the light of a study by Haas *et al* showing the significant impact of adolescent health on their social network [41]. Regardless of what caused poor health, adolescents who reported poor self-rated health was less likely to be selected by others to join in, and were therefore at risk of being socially isolated. This could also have been a reason for the young woman that rejected the GFD.

'I am gluten' were the words the women used to describe themselves and their disease. By using that phrase they actually say that they are what they cannot ingest (if they want to stay healthy). Further studies should investigate the impact such a phrase brings. Are they just words that ensure that others do not forget about their special food needs or does the phrase become a way to identify themselves with the disease? Or can the phrase be a way to diminish the impact the disease has? Since they reported that they sometimes felt an outsider in food related situations, the phrase, could also be a way to confirm others' views of them as deviant and as being an 'other' [32].

During the interviews, some concern was recounted about the prospect of becoming a parent diagnosed with CD and needing to shoulder the traditional role of being a mother. They seemed to have grown up in a traditional constructed gender order where being a mother or being a

father meant different responsibilities. The fathers were more seldom mentioned and often described as not being really involved in their dietary treatment. Their mothers were described having the care responsibility a pattern seen in previous research [42]. They were described as the ones who had initially taken action to make the treatment manageable for their daughters; this behavior was in line with earlier research which found that the mother was often responsible for 'normalizing' the family situation when someone in the family had been exposed to a food-related disease [43].

According to Connell (2012) categorical thinking about traditional gender norms can provide a way of understanding how we as women and men are gendered [13]. However, categorical thinking about gender does not show the dynamics of how gender norms are created and the conditions for change. At least when interviewed, these young women seemed to behave and prepare themselves for the future in different ways but aligned with the western stereotype of femininities. Our findings suggest that adherence to a strict GFD for young women is routinely obstructed by the socially expected norms of femininity.

5. Conclusion

The main theme of our findings, based on narratives from seven Swedish young women with CD, showed that their everyday lives were framed by social expectations about femininity encapsulated in social practice and in their personal relationships.

Clinical practice ought to be more self-reflective and consider how clinicians' own understanding of the GFD affects the treatment and what consequences different approaches could have for the patients. Our findings suggest that guidelines should take account of gender perspectives in order to strengthen the patients' self-image and personal possibilities. Group sessions could be implemented as an integral part of the treatment to meet CD peers to share experiences and develop strategies for coping with the diagnosis and for better long-term capacity to live with GFD in what is still a difficult food environment.

Abbreviations

Celiac disease (CD), Gluten-free diet (GFD), Exploring the iceberg of celiac disease (ETICS).

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Conflicts of Interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Abbreviations

Celiac disease (CD), Gluten-free diet (GFD), Exploring the iceberg of celiac disease (ETICS)

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