



# Seeking a New Normality: Masculinity, Interaction and a Gluten Free Diet

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**Abstract** From earlier studies, men diagnosed with celiac disease are known to be less troubled by their experiences of living with the disease than are diagnosed women. Previous studies, concentrating on men with celiac disease have been mostly quantitative, and have a bio-medical emphasis. The aim of this study was to explore the social experience of young men with screening-detected celiac disease and to highlight daily life situations five years after diagnosis. Seven young men, diagnosed with celiac disease when they were 13 years-olds through a large Swedish school-based celiac screening-study, were interviewed. The semi-structured interviews were analyzed from a gender perspective which resulted in three themes; being subjected to changes, striving for normality and emphasizing commitment. These were underpinned by several sub-themes. The young men dissociated themselves from being seen as a person with a life-long chronic disease. The analysis also showed that the young men's daily experiences of living with celiac disease largely depended on their use of characteristics known to be associated with masculinity: such as being self-assured, demanding, and behaving authoritatively. In food situations, where the young men had the ability to make use of such characteristics in their informal group, they experienced fewer negative aspects of the disease. If the young men did not hold a strong position in their informal group, their situation was insecure and vulnerable and this could lead to avoidance of contacts and social meal situations.

**Keywords:** *celiac disease, young males, gender, masculinity, social norms*

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## 1. Introduction

Celiac disease is a life-long disease affecting about 1-3 % of most populations with increasing incidence being reported from many countries [1,2,3]. The disease is characterized by villus atrophy of the intestinal mucosa and can develop any time throughout life if a predisposed individual eats gluten [4]. Symptoms and signs of untreated celiac disease are diverse, for example delayed puberty, anemia, osteoporosis, fatigue, gastrointestinal symptoms, depression, but the disease can also be asymptomatic [4]. Gluten is a protein complex found in foods containing wheat, rye and barley, commonly consumed in the Westernized culture as bread, bakery products and pasta. The only effective treatment is to keep a strict gluten-free diet which requires a great deal of personal commitment, self-control and responsibility often resulting in less than optimal adherence to the treatment [5,6].

Celiac disease seems to affect males and females somewhat differently and this is reflected in the literature. Males develop and are diagnosed with celiac disease to a

lesser extent than females [1,4]. Although the incidence for males is lower, there are a number of interesting implications for those who are diagnosed. Everyday Quality-of-Life (QoL) studies have shown that diagnosed boys/men are less negatively affected compared with females [7-13]. One study found that diagnosed boys report feeling happier than diagnosed girls and healthy controls (Ciacci et al., 2003). Men with celiac disease also report similar or higher QoL compared with healthy controls [8,10]. Height as a physiological measure has been studied in adult men and women with celiac disease with contradictory results [14,15,16,17]. According to a Swedish study, men with untreated celiac disease had the same average height as men in the general population [15]. However, other studies have shown that men diagnosed as adults were shorter than men in the general population [14,17]. A Finnish population study showed that only diagnosed men in the older birth cohorts (1948-1961) who had gastrointestinal symptoms were shorter than the general population [16]. In Western cultures it has been shown that height is not only a measurement, but has other implications, height in men is a relational asset and being tall is related to interpersonal dominance in various social settings [18,19].

Gender is not reducible to biological sex alone. Instead, the perspectives on men and women are mediated through different historical and culture contexts [20]. According to Connell, gender identity is socially constructed and provides a taken-for-granted framework of expectations [21]. The definition of a 'real man' or, as Connell designates it, *hegemonic masculinity*, is associated with men's authority and power over women and over other men such as, for instance, homosexual men. In most Western cultures, being white, heterosexual, independent, risk-taking as well as being emotionally and physically strong are characteristics consistent with a hegemonic masculinity. The concept of hegemonic masculinity is based on patterns that are socially constructed, related to historical and cultural contexts, and are thus subject to change over time. Hegemonic masculinity exists in relation to other masculinities, also described by Connell as complicit masculinity, subordinated masculinity and marginalized masculinity. The ways a man behaves, have consequences for his masculine identity. Connell suggest that, especially during adolescence, interpersonal interaction in informal groups is important for how one is defined in terms of different patterns of masculinity [22].

Influenced by Bourdieu's idea of 'symbolic capital', de Visser and McDonnell suggest an additional type of capital, a 'masculine capital' [23]. This 'masculine capital' gives men the opportunity to compensate a non-masculine behavior in one area with a more acknowledged masculine behavior in another, in order to uphold their masculine status [23]. As an example, cooking food is traditionally seen as domestic work carried out by women, with the food designed for the wellbeing and pleasure of others. In the media the picture of a man who cooks can compensate this female activity by cooking food in a more professional, solitary, selfish, and competitive manner [24]. At another level of behavior, young men are known to seek health care less often than young women when feeling ill. It has been suggested that men tend to ignore symptoms in order to construct for themselves an identity as being strong and proud, as this is seen as normative in our society [25].

Previous studies focusing on men diagnosed with celiac disease stress biologically based perspectives that contribute to the picture of living with the disease as rooted foremost in biology; which can be seen as an essentialist perspective [22]. Stressing the biological viewpoint often means that other important dimensions, such as managing the disease from gender, class and ethnicity perspectives, are ignored. In this paper, we focus on the contribution that gender perspective can bring to understanding the process of living with celiac disease. Specifically, we examine the interactional experiences of young Swedish men diagnosed with celiac disease by screening.

## 2. Methods

### 2.1. Participants and Sampling

To investigate how the everyday lives of young men were affected by celiac disease we initially invited participation from ten aged young men, aged 17-18 years,

who had all been diagnosed with celiac disease through a school based screening study entitled ETICS (Exploring the Iceberg of Celiacs in Sweden). This screening study had been undertaken in 2005-2006 in five geographically dispersed municipalities and involved children in the 6<sup>th</sup> grade of school i.e. 12-13 years of age. The screening study has been described in detail elsewhere [1].

Requirements for the present study were; being screened for celiac disease, being male, and still living in the same area where the screening had taken place. An invitation letter which described the aim of the study and provided information about the interviews was sent out to the ten men, and included an offer of two cinema ticket vouchers as thanks for participation. A few days after sending the invitation letter, the first author telephoned and asked if they would like to participate. Three men declined the invitation; one was not interested and two at first accepted the invitation but changed their minds before the interviews took place. Finally, seven young agreed to take part in the study. All participants attended upper secondary high school, were Swedish-speaking and lived with their families. Before the interview began, and before giving the written consent, each participant had their rights explained and were assured about confidentiality for the content of the interview. The study was approved by the Research Ethics Committee of Umeå (Dnr 2010-110-31 M).

### 2.2. Data Collection

To create the optimum conditions for discussion of subjective experience, each interview took place separately. The young men chose where the interview took place, resulting mostly in a school environment or library. The intention was to create a relaxed and friendly atmosphere to make the participant feel as comfortable as possible. Each interview was conducted by the first author and lasted about one hour. A semi-structured interview guide, drawn up by the authors was used during the interviews, focusing on the aim of this study. The overarching question asked for an account of what it was like to live with celiac disease and the resultant discourse included memories from the celiac screening, dietary changes, health, and how the celiac disease influenced their social life, health and perspectives on the future. To ensure the coherence of each interview, the concluding part began with a summary of the narrative by the interviewer, where the young men could, if necessary, clarify any misunderstandings. All interviews were audio-recorded.

### 2.3. Analysis

Data analysis followed the qualitative content analysis procedures detailed by Graneheim and Lundman [26]. Immediately after each interview, the recording was listened to by the interviewer and descriptive notes were written down. Interviews were transcribed verbatim and read repeatedly during the analysis by the first author, who used the specially produced software program for qualitative analysis ATLAS.ti v7 when labelling codes. Each interview was also read through by three trained co-authors independently, and comparisons of data interpretation were discussed in several meetings during

the analysis. The starting point of the analysis was a manifest inductive analysis. Thereafter categories were constructed based on content that shared a commonality. Themes and sub themes appeared on different levels as underlying meaning through the analysis; built on codes and categories, and were interpreted as the latent content of the text. The formulated themes are discussed here using a perspective of gender masculinity influenced by Connell [21] and by deVisser and McDonnell [23].

## 2.4. Trustworthiness

It is vital that trustworthiness is strengthened throughout the whole research process from data collection, over the analytical process, and into the reporting [26]. To achieve trustworthiness is to consider credibility, which refers to the aim of the study, data gathering and the analytical process. In order to maximize the potential of the study we intended to choose participants with varied experience. Therefore, it is considered to be a strength of this study that we addressed unknown young men living in different parts of the country, men we knew nothing about apart from their age range and participation in a screening study. The fact that only seven men participated can be seen as a small sample but the interviews were detailed and focused on engagement with celiac disease thus providing a robust set of participant accounts of their experiences. The analytical process with codes, categories and themes on

different levels was strengthened by the joint work of the authors; characterized by the intensive discussions of how to interpret our results. Trustworthiness was also improved by reflexivity throughout the research process; by repeated discussions within the research group where we reflected on how our own perspectives could affect our interpretation of the interviews. The research group represented a wide range of competencies including three registered dietitians, one registered nurse, and one pediatrician. The research group had experience from earlier gender studies, the application of qualitative research methods, and had undertaken both research and clinical work with persons having a celiac disease diagnosis. Dependability is another important dimension of trustworthiness. In this study this meant that we continuously discussed how our methods could affect the outcome of the interviews. Arguably there would be good transferability to other groups, given the context of gender and age.

## 3. Findings

The analysis of the young men's experiences of living with celiac disease resulted in three themes; being subjected to changes, striving for normality and emphasizing the commitment. Each incorporates several sub-themes.

Table 1. Themes and Sub-Themes

| Themes     | Being subjected to changes                      | Striving for normality   | Emphasizing the commitment                             |
|------------|---|--|--|
| Sub-Themes | Feeling ambivalence                             | Stressing normality  | Being actively engaged in practical tasks              |
|            | Experiencing physical and psychological changes | Feeling accepted or not feeling accepted   | Incorporating new motivational arguments for adherence |
|            | Looking for safety and security                 | Being 'one of the guys'<br>Experiencing support colored by a traditional pattern |  |

## 3.1. Being Subjected to Changes

### 3.1.1. Feeling Ambivalence

At 13 years old, the young men had been diagnosed with a chronic disease by screening. Becoming aware of having celiac disease was described with mixed feelings, from feeling relief and embracing the diagnosis to experiencing increased negative levels of stress and worry. After having been prescribed and started following the strict gluten-free treatment, the men recalled being worried and feeling unsafe, and they wondered how the treatment would affect their food intake and their social lives.

*But in the beginning it was really hard because I did not know it [dietary treatment], I did not know it, I was very insecure. (Participant 7)*

### 3.1.2. Experiencing Physical and Psychological Changes

Young men who, prior to the diagnosis, had withdrawn from physically activity due to insufficient stamina, described how tired they had felt.

*I was almost worn out, I was constantly tired, could not cope with anything. I was training a lot, but I had to finish with hockey for example. (Participant 2)*

Soon after they had started the dietary treatment, they were able to resume their physical activities. Those who could not recall being ill before they were diagnosed, felt that awareness of having the diagnosis, in itself, contributed to stress and stomach aches. One suggested that the stomach ache he had experienced after diagnosis might also be related to the low levels of fiber in the gluten-free diet.

At their first meeting with the health care team after diagnosis, doctors and dietitians had explained that their mood would improve as a feature of the new gluten-free diet. This was true, and they recalled becoming happier, and more alert, soon after they started with the gluten-free diet.

*It went quickly; as soon as I stopped [eating gluten] I became much better and happier and had energy to do more stuff. (Participant 1)*

The young men had also noticed that they had begun to increase height soon after they had started with the gluten-free diet, which was a welcome feature of their diagnosed status.

### 3.1.3. Looking for Safety and Security

Being subjected to these changes also meant that eating an ordinary meal was not as straightforward as it had been before the diagnosis. The young men had the intention to

follow the prescribed treatment, but they became aware that the strict diet could cause unexpected difficulties. For example, it could be hard to trust assurances from non-significant others, or new acquaintances, that they had strictly prepared gluten-free food. This could cause frustration and some of the men described the importance of feeling safe and secure could cause withdrawal from social situations.

The strict treatment entailed new kind of problem as the men grew older; they meant that being a teenager was different for them as compared with their peers, drinking beer for example. They pointed out the concerns about beer and gluten that their friends did not have to consider. They spontaneously highlighted questions they had come across when drinking beer as expressions of feeling insecure, and wanting someone to turn to for information.

*Then there's this thing with the beer... I do not really know if you can drink beer or not and how large amount (of gluten) you get, if you drink, whatever you drink...and I do not know where to find out, or where to get the information. (Participant 5)*

When contradictory messages about the treatment were given by health care personnel it was confusing. One of the young men described how, during a meeting with a dietitian, he had been told that it was okay to transgress the strict regime of the gluten-free diet once in a while. He had considered what the dietitian had meant by such a suggestion, and had decided that it has been both inappropriate and confusing to suggest this.

*When we were at the dietitian's, she said, 'It doesn't matter if you cheat a little bit' but I don't understand way she said that, the reasoning was quite unprofessional. (Participant 5)*

## 3.2. Striving for Normality

### 3.2.1. Stressing Normality

The young men seemed to have integrated celiac disease into their identities while, at the same time, they tried to play down the importance of this diagnosis in front of others. They emphasized that their lives were the same as others.

*...I'm used to it now, I had it for such a long time that I can do it [gluten-free food] without thinking. You just have to remember to be a little bit extra cautious, and then it's not a major problem. (Participant 6)*

This attitude was displayed, for instance, when one of the young men described how other people said it would be very challenging to be forced to eat his diet. He did not want to exaggerate difficulties so he dismissed the problems with the treatment.

*I've heard people who quite spontaneously said: 'I really would not like to have... I mean... I would not be able to change the diet like that' ...but I usually reply: 'I don't think it is so difficult'. (Participant 7)*

Young men stressed their resistance to the view of them as different because of celiac disease. They meant that it was the food that was different, not them.

*Not that I'm different ... just because I'm gluten intolerant ... it is just that I do not tolerate flour. (Participant 6)*

Another common tactic to avoid being seen as different was not to tell new acquaintances of their diagnosis until

they absolutely had to: for example, when they were going out to have a meal together.

At times when they had been particularly worried about celiac disease problems and their dietary treatment, the young men recalled that they had deliberately avoided any mention of their feelings; instead they pointed to their normality. When asked if they had anyone that they turned to when considering their daily experiences of living with celiac disease they seemed to hesitate.

*No, it was not as if I wanted to talk about it, it is more in hindsight I think it was pretty damn hard. (Participant 7).*

Parents, peers diagnosed with celiac disease, and the Celiac Association [Celiakiförbundet], were mentioned as being supportive, but they stated that they found it difficult to accept help from others.

At the time of the interviews, the young men were attending secondary upper high where all pupils were given a hot school lunch every day. To get their gluten-free lunch, they had to use a special queue in the school canteen, which pointed them out as having special meal needs and not being seen as 'normal'. However, standing in the special queue could also provide an opportunity to initiate social contacts with others having the same diagnosis and supporting feelings of relative normality.

*At first I thought it would be really hard to stand in a specific line for food (in the school canteen) where others could see that I was gluten, but then it was another guy in my class who also was there, so it was like nothing. (Participant 2).*

### 3.2.2. Feeling Accepted or Not Feeling Accepted

Being seen and accepted by friends as someone having celiac disease was for most of the young men described as a matter of course. At the same time, their narratives showed that acceptance seemed to occur on different levels. Such levels were interpreted from the way they outlined their relationship with friends. It would require a relatively high status within an informal group to negotiate with friends about where to go and what to eat, thus setting limits on which restaurant to go to. Also, when friends were described as choosing restaurants serving acceptable gluten-free alternatives and deliberately avoiding places that served non-tasty gluten-free bread it pointed to feelings of accommodation and being accepted.

*We never eat at Subway, I resist it. They have something that is gluten-free, but it is extremely boring. So if they are going there, I say... "No, I will not go; you have to eat without me". (Participant 7)*

Somewhat different was the situation for men who stated that they were welcome to join in, when their friends went out to eat, but whose friends did not consider the food limitations a gluten-free diet brought. Since the only way to 'hang out' with those friends was to accept their choice of place to eat, these young men demonstrated peer group acquiescence and did not have an influential position.

*It can be boring at times, you know, if they [the restaurant] do not have anything good at all, or nothing at all... but you can still buy a drink, so it's cool. (Participant 3)*

An understanding of celiac disease dietary restrictions was sometimes tentative, or at least framed that way in the

teasing and bullying that could be associated with gluten-free food.

*It's often that the guys in the class are joking like: "You've gluten intolerance" and "Oh, you can eat something" [both said in a teasing voice], it's a problem every day. (Participant 4)*

One young man recalled a situation in high school when he had been deceived at a home-economics cooking lesson. A classmate had deliberately replaced gluten-free pasta with ordinary pasta and failed to mention it until he had finished the meal.

There could also be institutional rather than interpersonal problems: one participant had not had the opportunity to eat a gluten-free school lunch in the same canteen as his peers because of the way the meals service was organized at his school. Despite promptings, this was not addressed by the school board and he felt this arrangement had adversely affected him. Being unable to eat with his peers had resulted in not having the same opportunity to build relationships at meal times with his informal group.

### 3.2.3. Family Support and Traditional Domestic Role Allocation

Participants recalled how their families had made an effort of trying to make their life with celiac disease as 'normal' as possible. Mothers, in particular, were described as having the overall responsibility to normalize their situation. They were the ones to talk about issues concerning celiac disease, e.g. practical issues such as new recipes, tax-financed economic support from the government, searching for new places where gluten-free alternatives were being served. Mothers were also likely to prepare sons for the responsibility of their own dietary treatment.

*She [mom] wanted to be supportive as well, so she would not let me be ... so I had to take care [learning about the gluten-free diet]. I think that was very good. (Participant 1)*

In their narratives, the young men described their families as having a traditional gender division of labour. Mothers were mostly described as the main housekeeper, shopping for groceries, finding new recipes, cooking food and so forth.

*Mom is more familiar... not to say that women and men are different ... but it feels as if women tend to usually be more familiar with this stuff (diets). (Participant 4)*

By contrast, only a few fathers were mentioned undertaking any special actions concerning their son's dietary treatment. In spite of this, the young men seemed to take for granted that their fathers were supportive, although they were to some extent described as being silent, careless and not especially responsible.

*Dad is a bit sloppy... he can, if we are sitting in a restaurant and the chef explains that the sauce ought to be gluten-free, and my mom and I feel that he [the chef] doesn't know what he's talking about... but my dad might say, "that's great let's have it". (Participant 4)*

Fathers who baked and took a more active part in their son's dietary treatment were also mentioned. However, their practical engagement in dietary treatment seemed to be more intermittent compared with that of the mothers. As opposed to mothers, no fathers were described as the one the young men could turn to if they had worries about their life and being diagnosed with celiac disease.

## 3.3. Emphasizing Commitment

### 3.3.1. Being Actively Engaged in Practical Tasks

Participants described themselves nowadays as being positively engaged in practical tasks concerning their gluten-free diet. They commented that they had actively placed gluten-free food at their friends' homes. They outlined how they purposefully tried to expand their personal menu of specially manufactured gluten-free products by being willing to try new products on the market. Despite the increased range of specially manufactured gluten-free products now available, they thought that home-baked bread was mostly superior in taste. Therefore some of the men had started to bake for themselves, mostly cakes and muffins. However, problems were experienced with the gluten-free mixes, which they found hard to handle, and therefore preferred products like 'shake 'n bake mix'.

In school the young men had realized that they needed to be proactive in order to improve their gluten-free options. As an example, the obligatory practical home economics lessons could entail special difficulties, and one participant described how, in elementary school, he had to bring the gluten-free mix himself to school from home when baking bread. Another recalled that he had, at first, been a passive spectator when his peers baked since there had not been any gluten-free mix to use. After he had questioned this lack of gluten-free products it had been rectified and the school had bought gluten-free products for him to use.

During their spare time, all participants had experienced sometimes being without gluten-free alternatives when going out to eat. This had forced them to adjust their expectations to the available gluten-free choices such as kebab plates instead of a falafel sandwich or pizza. Restricted food choices occasionally forced compromises but always there was the probability of inconvenience as compared with peers: one missed being able to buy a 'grab and go' lunch.

*It's very convenient to take a falafel and ride the bike while eating... it is a little bit harder to eat the kebab on a plate and ride [your] bike. (Participant 5)*

### 3.3.2. Incorporating New Motivational Arguments for Adherence

The dominant perspectives after being diagnosed involved taking an active stand and making a personal commitment to follow the strict gluten-free treatment. However, having to accept a strict gluten-free diet was described as hard to accomplish and there were examples of having eating gluten after starting the dietary treatment. Some of the men described how they could react strongly if by accident or mistake ate gluten containing food. One explained that if he ever considered transgressing the food rules, he started to feel nauseated, which worked in favor for his strict compliance. Another recalled when he had been alerted to the fact that a pie he just had eaten contained gluten. The awareness had made him react strongly, described as cold sweats and had provoked an emetic reflex in order to get rid of the gluten.

Strict compliance was seen as the only secure way to avoid adverse health consequences which they believed might occur in the long run if they neglected the dietary treatment.

*I just know that if I eat non-gluten-free products I could get diabetes when I get older ... and that's a reason enough for me. (Participant 5)*

There were also indications they were motivated by a belief that strict adherence increased the chances of reaching their individual maximum height. One man considered the possibility of giving up the strict diet when he reached adulthood and his final height.

*Actually I want to eat gluten-free diet until I've finished growing, it is important for me to grow. (Participant 4)*

Comparison served to reinforce their dietary compliance efforts: all knew someone else having celiac disease and they paid attention to how well they dealt with the dietary treatment. Those who did not comply were seen as being careless, or simply not willing to face the social consequences of compliance. They told stories of others who had abandoned the gluten-free treatment or those who saw their celiac disease as extremely problematic.

## 4. Discussion

Analysis of the interviews had resulted in three themes; being subjected to change, striving for normality and emphasizing commitment. These themes are discussed here in terms of the gender perspective elaborated by Connell and Messerschmidt [23] and de Visser and McDonnell [27].

The first theme '*Being subjected to changes*' reflected the diversity of experiences among study participants when they were diagnosed with celiac disease. These male experiences can be studied in terms of the social construction of masculine identity. In the Western society, hegemonic masculinity is consistent with strength and health [27], and, conversely any reduced health status in men is associated with vulnerability and weakness which can convey diminished masculine capital [28].

It should be noted that the men in our study were diagnosed by screening and had not themselves sought help for specific gastrointestinal disorders. The diversity of their narratives about the (early) experience of being diagnosed could therefore be seen as a result of how they had perceived their overall health before diagnosis. Those who reported that prior to diagnosis they had been extremely tired, easily exhausted and had given up physical leisure activities, experienced being diagnosed as a positive turning point. The diagnosis and the dietary treatment offered them opportunities to regain strength and become physically active. By contrast, those who described facing the diagnosis in a more negative tone indicated that stressors and worries had increased at that point.

The diverse experiences of these young men could be explained in terms of the theory of masculinity capital and 'man points' described by de Visser and McDonnell [23]. The men who recalled a positive turning point and who gained strength added 'man points' and gained masculine capital. Those who recalled diagnosis as an adverse experience lost 'man points' and therefore had a reduced masculine capital. Experiencing increased levels of physical strength, especially in relation to competitive sports, is often considered part of the masculine ideal in Western societies and physical strength seems to add highly valued 'man points', a pattern also seen among those in this study.

They valued their ability to increase height as very important. Being reasonable tall was seen as a masculine ideal and a way for the men to improve their masculine capital. One of the classical signs and symptoms of having celiac disease as a child is short stature [4]. As mentioned earlier, one participant even pondered the possibility of ending the gluten-free diet when he had reached his adult height. Our analysis also showed that their emotional strength - such as being more cheerful - had increased when they started to follow the strict dietary treatment. Emotional strength is a feature known as a masculine characteristic ideal which contributed to the masculine capital.

All the men in our study expressed the intention of keeping to a strict gluten-free diet. Previous studies had shown that many patients with celiac disease are not compliant with a strict gluten-free diet [5], and screening-detected patients have earlier been described as being at risk of poor adherence [29]. This has been questioned by other studies comparing adherence in both symptoms- and screening-detected patients, stressing adherence does not differ between the groups [12,30]. However, what does it mean, from a young man's perspective, to be compliant with a strict gluten-free diet? Having strong willpower, behaving determinedly, being dedicated, strong and firm, all characteristics which work in accordance with the norm of hegemonic masculinities and also in favor for strict adherence [6,31]. Being in an environment where these features could develop and grow suggests that by strictly following a dietary treatment, these young men could, from a gender perspective, regain some of the 'man points' they had lost when diagnosed.

All participants in the present study recalled that they knew others who were diagnosed with celiac disease. Some of these were described as deviant, meaning that they were not strictly compliant to the gluten-free diet. Young men in our study could create a sense of order in their social world when they could trust to masculine ideals such as being dedicated, despite the personal cost, and thereby experience feelings of gaining 'man points' whilst being compliant [32]. By seeing the deviants as an example of *failing* behavior the men could negotiate their own masculine identity and stress their own strength while disassociating themselves from others.

As a theme '*Striving for normality*', indicated that they did not consider celiac disease as an *ordinary* chronic diseases: if they just remained compliant with the strict gluten-free treatment they considered themselves as healthy as anyone else. This could be a reason for the young men to strongly oppose being seen as different. Another reason for striving for masculine normality could be that they did not want to show weakness. Their confident attitude signaled "being like everybody else" and specifically emphasized that it was just the food that was different: the disease was something to handle and deal with as undramatically as possible. These findings are in line with Williams' studies on adolescent boys diagnosed with asthma and diabetes [33]. In order to avoid the stigmatizing impact a chronic disease can have, the boys in her study made every effort to keep their illness separate from their personality. This behavioral pattern has also been shown among adult men by Hallert et al. [8].

Connell's theory of hegemonic masculinities and the constructions of masculinity, suggests that masculinities could also "be defined at the level of interpersonal interaction, for instance in informal peer group life" [27], [34]. According to our analysis, the position our participants held in their informal peer group, had an overwhelming impact on their experience of the situation. Those with a strong position in their informal group had the space to strive for normality by being able to negotiate with peers and make demands about gluten-free food. They could, by using these masculine attributes as strength, gain further 'man points'. Those who expressed marginalization in their informal group had no room to use similar masculine attributes. They had a vulnerable position and, in accordance with Connell's theory, that means that they had few tools to alter their situation, and their masculinity could be seen as subordinated or as marginalized.

Men with celiac disease are mostly presented in medical literature as being less troubled in their everyday life than women [7,8,9,10,11,13]. Therefore an important finding in our study is to illustrate the heterogeneity of male experiences: some participants described their situation as tough and socially uncomfortable. Independent of their earlier status in the informal group, their status seemed to have further decreased after diagnosis, and experiences of being bullied, teased and deceived made them cautious about these social contacts. For adolescents, such stressors are known to lead to feelings of being stigmatized [35].

Questions raised by our participants included compliance: to what extent could gluten be consumed? As an example was the young men's interest in how to handle alcoholic beverages. This illustrated insecurity about how much beer they could drink without gluten-related problems. In Western societies, alcoholic beverage consumption is known to be connected with masculine identity, and not being able to drink with friends means a loss of social, cultural and masculine capital [23]. In Sweden, the legal age limit for drinking alcohol is eighteen. Could this be a reason why the young men did not automatically address their questions about alcohol to the dietitian or the doctor? Health care personnel who interact with men having a celiac diagnosis might consider the question of gluten and alcoholic beverages that are something of interest for adolescents – even if they are under the legal age for alcohol consumption.

Although strict adherence to gluten-free diets seemed important, our findings suggest this may become very rigid and induce great concern about any consumption of gluten in their diets. Such concerns may lead to a mistrust of anyone who offers gluten-free products for consumption and jeopardize the normal socialization of adolescence. A dietitian, described in the narratives, had suggested that a strict diet did not always have to be very strict. This caused frustration for the young man in question. It is possible this was said by the dietitian in order to reduce the potential for inconvenience and soften the guidelines for everyday life, we do not know. However, it did not work for this patient, and might be a signal for health care professionals to reflect on how we define and address 'strictness' when it comes to gluten-free diets.

The theme '*Emphasizing the commitment*' illustrates how the participants in the study frequently highlighted their own effort by describing themselves as taking action.

This was described as being proactive in order to improve the gluten-free menu, making a personal commitment for the strict compliance and placing gluten-free alternatives at their friend's home. This pattern is in line with Hallert et al.'s finding that the men with celiac disease were likely to take a problem-oriented approach to manage the difficulties caused by the disease [36]. The young men in our study kept trying to increase the range, and improve the taste, of specially made gluten-free food by both shopping and baking. In the literature, men's cooking activities seem to be more correlated with enjoyment, and cooking food when in the mood [37]. Men have traditionally been seen as breadwinners with women responsible for the home and the preparation of food, but this pattern seems to be changing and today men more frequently prepare food in a home setting [38]. Szabo suggest in her study of masculinity and home cooking that men who live in a context where egalitarian attitudes are important could receive more praise when they got involved in home cooking [39].

Limitations in our study are that we have not studied the influence of culture, socio-economic status, place of residence, and ethnicity for the young men's experience of living a daily life diagnosed with celiac disease. Also, Swedish culture is known for being one of the most egalitarian societies in the world which could in some ways have implications that hinders comparison with other young men with celiac disease in a different culture, in a different context.

## 5. Conclusion

Young men's experiences of living with celiac disease are greatly affected by the position they hold in their informal groups. If their status was high and they could make use of this attribute in line with a dominant masculinity, 'man points' could be obtained. By contrast, if the young men did not hold a strong position in their informal group, they could feel insecure and vulnerable due to their dietary regime. Such interactional difficulties could lead to withdrawal from everyday contacts, and social meal situations. The negative effects being diagnosed with a chronic disease had on their perceived masculinity, could however be compensated for by being firm, making demands and sticking to the diet. These behaviors allowed an accrual of 'man points' due to their masculine connotations. Healthcare professionals should be aware of the ways gender norms affect every day lives and treatment compliance in order to better strengthen resolve and empower patients.

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

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