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# Social Implications of Celiac Disease or Non-celiac Gluten Sensitivity

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**Abstract** Research has described the perceived social restrictions that people who suffer from celiac disease can experience, but never investigated their actual amount of social contacts as compared to a healthy population. Therefore, we focus on the question whether people who suffer from celiac disease or non-celiac gluten sensitivity have less informal social capital (e.g. contacts with friends and family) than a healthy population and, if so, which health related factors can explain these differences in social capital. With the aid of the Dutch Celiac Association, we recently gathered high quality data. Results show that people who are diagnosed with celiac disease or NCGS indeed have less informal social capital than a healthy control group. This can be explained partly because the former more often suffer from depression, poor subjective health and another chronic condition. Moreover, it appears that demographic factors, such as gender, age, having children and marital status, reduce the initial relationship completely. These demographic factors thus play a more important role. As yet, these findings may help healthcare professionals to interpret social consequences of celiac disease and non-celiac gluten sensitivity in a broader sense.

**Keywords:** *health related explanations, differences, informal social capital, celiac disease, non-celiac gluten sensitivity*

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## 1. Introduction

The impact of celiac disease on people's daily lives, especially health related quality of life, has been investigated regularly. Some research shows that a gluten free diet can significantly improve quality of life after celiac disease diagnosis [1,2]. Others showed that celiac disease and a gluten free diet does entail many social restrictions, such as difficulties while eating out or traveling [3,4,5]. Many scholars have stressed the importance of studying social and psychological impacts of suffering from celiac disease [6,7]. Despite the fact that social restrictions, that can be present when suffering from celiac disease, are described in several studies, it has never been investigated if celiac disease also has a negative impact on the formation of informal social capital, namely contacts with friends, family, neighbors and colleagues.

When it comes to social contacts we explicitly focus on informal social capital because it has a strong theoretical and methodological base in research which can be applied well to the subject of this research. Social capital was first conceptualized by Bourdieu [8] and has been complemented by many others. Informal social capital consists of informal social bonds between individuals (in contrast to formal social capital which consists of civic participation in formal organizations) [9]. Many resources that can be invested in social relations, such as economic

means (income) or cultural means (knowledge on a variety of subjects, cultural competences related to a certain social status) are important to attain social capital. A lack of these resources could reduce informal social capital [10,11]. It has been argued that good health can also be seen as a resource that fosters social capital because it enables people to participate in social events [12,13]. Consequently, a lack of health can be a restriction of this resource.

Therefore, we argue that having celiac disease can be seen as a lack in resources as well, because of two reasons. First, the gluten free diet can be difficult to follow and can be experienced as restrictive [14]. A dietary restriction such as a gluten free diet can have a negative impact on the ability to dine out, eat at a friend's place or travel [3]. The restrictions that a gluten free diet imposes on eating outside of the home may impact someone's opportunities to socialize, since social events often involve food. This could reduce the informal social capital of people who suffer from celiac disease or NCGS. Second, celiac disease is a chronic condition. Although complaints should be manageable by following a gluten free diet, some people still experience health complaints [15,16] which can impose restrictions on people's daily lives, including opportunities to gain and maintain informal social capital by participating in social events.

Different studies have shown that people with celiac disease are more vulnerable to other health related issues such as depression [17], a variety of physical symptoms

[16], poor subjective health [18,19] or other chronic conditions [20]. These factors can induce (extra) difficulties in investing in and maintaining social relations and may have a negative effect on social participation [13,21,22,23,24,25]. We will take these individual health related characteristics into account as possible explanations for differences in social capital between people who suffer from celiac disease and a healthy control group. Since there appear to be more reasons than celiac disease to adopt a gluten free diet, mainly NCGS, we will take this group into account as well, in contrast to prior research.

Consequently, we address the following research questions: (1a) *To what extent do people who suffer from celiac disease or NCGS differ from the general population in terms of informal social capital?* and (1b) *If there are differences, to what extent can they be explained by individual (health related) characteristics?*

## 2. Data and Measurements

### 2.1. Data Description

For this research we made use of non-random convenience sample utilizing the membership file of the Dutch Celiac Association. We sent an e-mail with a questionnaire to all members who stated they would be willing to participate in any scientific research. Thereafter, we asked all respondents to send a questionnaire to one friend or acquaintance. With this approach, our goal was to find a healthy control group, which resembled the people who suffer from celiac disease or NCGS on some important characteristics such as gender and age. The questionnaire for friends or acquaintances was similar to the questionnaire received by people with celiac disease or NCGS; moreover, we asked about the relationship with the person who sent the respondent the questionnaire. We left out specific, non-applicable questions about celiac disease or NCGS and the gluten free diet.

The Dutch Celiac Association had approximately 17.000 members at the time of the data collection. Of these members 4.673 stated they were willing to take part in scientific research and were sent the questionnaire and letter. In total, 1.167 members filled in the questionnaire. Consequently, the response rate is 25 percent<sup>1</sup>. It was not possible to determine how many people sent the questionnaire to a friend or acquaintance, so the response rate of this questionnaire cannot be estimated. This questionnaire was filled in by 163 people.

It was not possible to test for representativity extensively, because we only know something about the national prevalence of celiac disease regarding gender. Celiac disease is two to three times more common in women than in men [34]. The people who filled in the first questionnaire through the Dutch Celiac Association seem to match these criteria: 73.9 percent is female and 26.1 male, which resembles the gender specific prevalence of celiac disease in the total population.

After exclusion of all cases with missing values (except for income), the dataset consisted of 1256 people, of which 1097 filled in the first questionnaire and 159 filled in the second questionnaire.

### 2.2. Operationalization

We measured informal social capital with the following questions: How often do you have personal contact with the following people: (1) family, (2) friends, (3) colleagues/classmates and (4) neighbours. We explicitly stated that this question only covered offline, face to face contact. A factor analysis and reliability check showed that creating a scale measuring contact with family, friends and colleagues/classmates led to the highest reliability ( $\alpha=0.49$ ). Although a Cronbach's alpha with a minimum value of 0.60 is desirable [26], we decided to construct a scale with three variables (leaving the item about neighbours out) to take into account theoretical as well as methodological considerations. On this scale a higher score means a higher level of informal social capital.

We asked respondents if they had celiac disease, NCGS or none of these diagnoses. Furthermore, we asked about how their diagnosis was given. We based these questions on the current guidelines for the diagnosis of celiac disease [27,28] and on the Salerno criteria [29] when it comes to NCGS. To determine which people did not suffer from celiac disease or NCGS, we included the respondents of the second questionnaire, who indicated not to follow a gluten free diet. Consequently, we distinguished four groups: (1) people who suffer from celiac disease (official diagnoses) who eat gluten free, (2) people with an unofficial celiac disease diagnosis who follow a gluten free diet, (3) people who suffer from NCGS (official and non-official diagnoses) who eat gluten free and (4) people without celiac disease or NCGS who do not follow a gluten free diet.

Depression was measured by the CES-D scale (Center of Epidemiological Studies Depression Scale). We found these questions to form a reliable scale ( $\alpha=0.81$ ) on which a higher score means a higher amount of depressive symptoms, including for example: feelings of sadness, loneliness or depression, problems with sleeping and troubles to 'get going'.

To measure physical health we asked people how often in the past four weeks (on a four point scale from *almost never* to *almost always*) they experienced certain physical symptoms that are related to celiac disease, namely: *pain in general, abdominal complaints* [16], *fatigue* [30] and *problems with concentrating* [20]. A reliable scale was made with a Cronbach's alpha of 0.75 which indicates the amount of physical problems people experience. A higher score means that someone experiences more symptoms.

We measured subjective health with the question '*How is your health in general?*' [31]. Respondents could answer on a five point scale ranging from *very bad* to *very good*. Furthermore, we asked all respondents whether they had a chronic condition or other food-intolerance/allergy. Answer categories were *no* or *yes*, namely: *diabetes, thyroid disease, Dermatitis Herpetiformis, rheumatic disease, lactose intolerance* or *other*, namely. For the analyses, we divided people into two categories: those who did have another chronic condition and those who only had celiac disease or NCGS, or did not have a disease at all (in case they belonged to the healthy control group).

As control variables, we included several resources known to be related to informal social capital. We took

<sup>1</sup>  $((1.167/4.673)*100)$

into account education, measured with the ISCED-scale [32] composed into three dummy categories ((1) *primary and lower secondary education*, (2) *upper and post-secondary education*, (3) *tertiary education, first and second stage*) on the basis of linearity checks. Income was classified as *below average* (up to 2100 euros a month) and *above average* (more than 2100 euros). Extra categories were created for people who did not know or did not want to indicate their income. Regarding marital status, we distinguished people who are *single, with a partner but not married or cohabiting, married or cohabiting, divorced, and widowed*. Furthermore, we made a distinction between people who have *no children, children who live at home or children who do not live at home*. Also, we asked respondents about how often they attend religious services: (*almost*) *never, a few times a year, around once a month or around once a week*. At last, we included *gender* (1=female) and *age* (18 to 93).

Descriptive statistics of all variables can be found in Table 1 and Table 2.

**Table 1. Descriptive statistics of continuous variables**

	Min.	Max.	Mean	S.D.
Informal social capital	0	6	3.17	1.05
Depression	0	2.75	0.75	0.48
Physical symptoms	0	3	0.88	0.64
Subjective health	0	4	2.66	0.74
Church attendance	0	3	0.67	1.07
Age	18	93	53.92	16.44

N=1256.

**Table 2. Descriptive statistics of categorical variables**

	N	% cat. 1
Celiac disease/NCGS		
• No CD/NCGS	159	12.7
• Official celiac disease diagnosis	920	73.2
• Unofficial celiac disease diagnosis	79	6.3
• NCGS	98	7.8
Income		
• Below average	341	27.1
• Above average	724	57.6
• Don't know	43	3.4
• Don't want to tell	148	11.8
Level of education		
• Primary and lower secondary	228	18.2
• Upper and post secondary	395	31.4
• Tertiary	633	50.4
Having a (chronic) condition		
• no	661	52.6
• yes	595	47.4
Gender		
• male	328	26.1
• female	928	73.9
Marital status		
• Married or cohabiting	866	76.1
• Together not married/cohabiting	88	7.0
• Divorced	36	2.9
• Widow	45	3.6
• Single	143	11.4
Having children		
• No children	388	30.9
• Children at home	327	26.0
• Children not at home	541	43.1

N=1256.

### 3. Results

For our analyses we used linear regression analysis, performed in IBM SPSS Statistics 21.

#### 3.1. Celiac Disease/NCGS and Informal Social Capital

First we tested the bivariate relationship between suffering from celiac disease or NCGS and informal social capital in Model 1 of Table 3. This shows that people who suffer from celiac disease (officially diagnosed) do actually have less informal social capital than the healthy control group ( $b=-.302$ ). People with an unofficial celiac disease diagnosis and NCGS have less informal social capital as well ( $b=-.299$  and  $b=-.341$ ).

#### 3.2. Mediating Factors: Depression, Physical Symptoms, Subjective Health and Other Chronic Conditions

Model 2 to 5 show the effects of depression, physical symptoms, subjective health and having (another) chronic condition. In Model 2 it can be seen that people who experience depression have less informal social capital ( $b=-.302$ ). Depression reduces the initial relationship between suffering from celiac disease or NCGS and informal social capital with 13.6<sup>2</sup> percent (for people with an official celiac disease diagnosis), 15.7<sup>3</sup> percent (for people with an unofficial celiac disease diagnosis) and 27.0<sup>4</sup> (for people with NCGS) percent. It appears that physical symptoms do not influence the amount of informal social capital (Model 3) and that people who report to have a better subjective health have more contacts with friends, family and colleagues/classmates ( $b=.164$ ) (Model 4). Also, subjective health explains 17.8<sup>5</sup> (official celiac disease diagnosis), 14.7<sup>6</sup> (unofficial celiac disease diagnosis) and 31.1<sup>7</sup> (NCGS) percent of the initial relationship between suffering from celiac disease or NCGS and informal social capital. Model 5 shows the effect of having another chronic condition. It appears that people who have a chronic condition (next to celiac disease or NCGS) have less social capital ( $b=-.231$ ). Having another chronic condition reduces the initial relationship with 20.8<sup>8</sup> (official celiac disease diagnosis), 27.1<sup>9</sup> (unofficial celiac disease diagnosis) and 36.4<sup>10</sup> (NCGS) percent.

To investigate the effects of depression, physical symptoms, subjective health and (other, chronic) conditions more in depth, we use a method described by Preacher and Hayes [33] which not only checks the significance of these factors on informal social capital, but also the effect of having celiac disease or NCGS on these mediating factors (Figure 1).

<sup>2</sup>  $(-.302)-(-.261)/-.302*100=13.6\%$

<sup>3</sup>  $(-.299)-(-.252)/-.299*100=15.7\%$

<sup>4</sup>  $(-.341)-(-.267)/-.341*100=21.7\%$

<sup>5</sup>  $(-.302)-(-.248)/-.302*100=17.8\%$

<sup>6</sup>  $(-.299)-(-.255)/-.299*100=14.7\%$

<sup>7</sup>  $(-.341)-(-.235)/-.341*100=36.3\%$

<sup>8</sup>  $(-.302)-(-.239)/-.341*100=20.8\%$

<sup>9</sup>  $(-.299)-(-.218)/-.299*100=27.1\%$

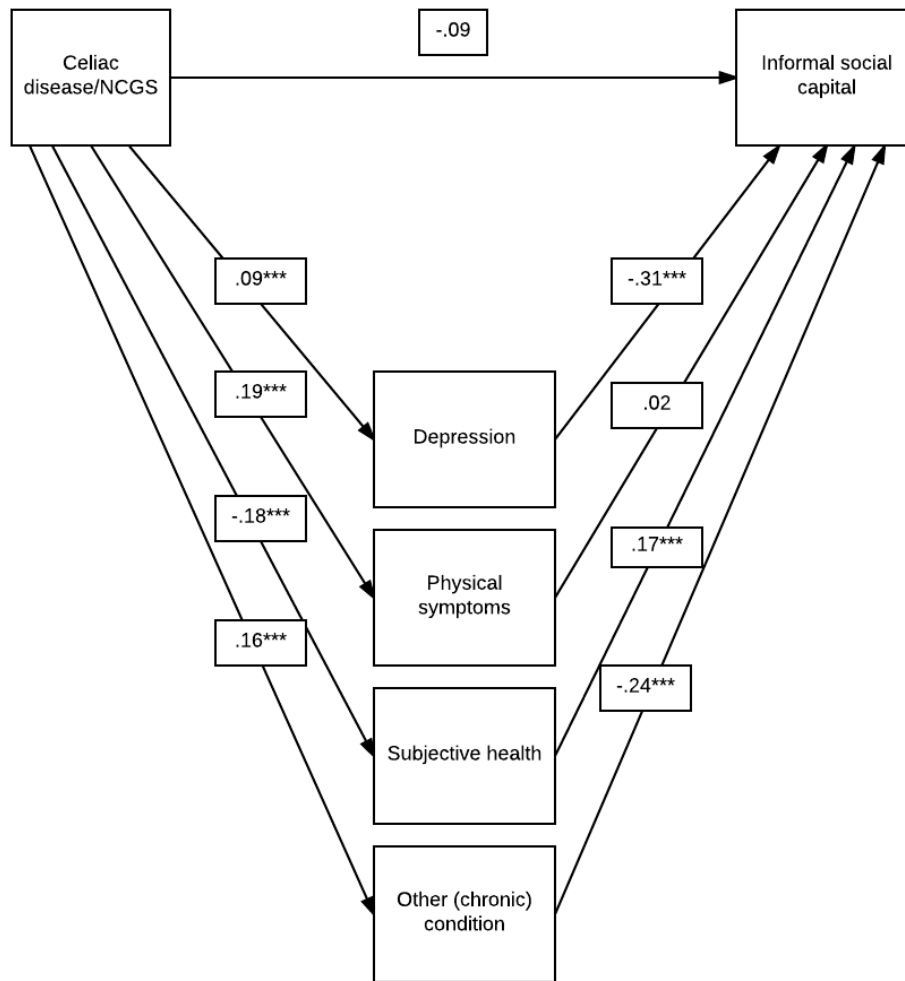
<sup>10</sup>  $(-.341)-(-.217)/-.341*100=36.4\%$

**Table 3. Results linear regression analysis of the effect of suffering from celiac disease/NCGS on informal social capital**

	Model 1		Model 2		Model 3		Model 4		Model 5		Model 6		Model 7	
	B	S.E.	B	S.E.	B	S.E.	B	S.E.	B	S.E.	B	S.E.	B	S.E.
Intercept	3.438***	.083	3.590***	.091	3.452***	.088	3.022***	.153	3.486***	.084	4.893***	.180	4.856***	.240
CD/NCGS (ref = healthy control group)														
Official CD diagnosis	-.302***	.090	-.261***	.090	-.297***	.091	-.248***	.091	-.239***	.091	-.091	.083	-.014	.083
CD unofficial diagnosis	-.299**	.145	-.252*	.144	-.293**	.145	-.255*	.144	-.218	.146	-.189	.131	-.108	.130
NCGS	-.341**	.135	-.267**	.135	-.327**	.139	-.235*	.137	-.217	.138	-.216*	.122	-.085	.125
<i>Mediators</i>														
Depression			-.302***	.061									-.345***	.068
Physical symptoms					-.022	.047							.061	.057
Subjective health							.164***	.041					.075	.046
Having a (chronic) condition (1=yes)									-.231***	.061			-.100*	.058
<i>Control variables</i>														
Level of education (ref = primary/lower secondary)														
Upper/post secondary											.064	.083	.053	.082
Tertiary											-.016	.082	-.029	.080
Income (ref = below average)														
Above average											.068	.073	.018	.073
Don't know											-.014	.154	-.020	.152
Don't want to say											.121	.098	.076	.097
Marital status (ref = single)														
Married or cohabiting											-.312***	.103	-.365***	.102
Together with partner (not married/cohabiting)											-.131	.130	-.195	.128
Divorced											-.430**	.183	-.386**	.181
Widowed											-.188	.173	-.238	.170
Having Children (ref=no children)														
Children living at home											.070	.079	.063	.077
Children not at home											.216**	.087	.177**	.086
Gender (1=female)											.106*	.064	.160**	.065
Age											-.030***	.002	-.029***	.002
Church attendance											.028	.025	.023	.025
R <sup>2</sup>	.009		.029		.010		.022		.021		.218		.249	
Adjusted R <sup>2</sup>	.007		.025		.006		.019		.017		.207		.236	

For depression, subjective health and having another chronic condition a significant and full mediation effect was found. This means that these factors significantly influence informal social capital, but also are influenced by suffering from celiac disease or NCGS. The effect of

physical symptoms on informal social capital appeared to be insignificant. However, the extra analysis, as showed in [Figure 1](#), shows that people who suffer from celiac disease or NCGS do tend to experience more physical symptoms.



**Figure 1.** Preacher and Hayes analysis on the mediating factors of the relationships between celiac disease or NCGS and informal social capital

### 3.3. Demographic Characteristics

The influence of relevant demographic characteristics is shown in Model 6. Including these characteristics reduces differences between suffering from celiac disease or NCGS and informal social capital to non-significance, implying that the initial differences are due to these demographic factors.

It appears that people who are married or cohabiting and people who are divorced see their friends, family and colleagues/classmates less often than singles ( $b=-.312$  and  $b=-.430$ ). Having children who do not live at home has a positive effect on informal social capital ( $b=.216$ ). Lastly, women and younger people have more frequent contact with friends, family and colleagues/classmates. ( $b=.106$  and  $b=-.030$ ).

In Model 11, all mediators and control variables are shown. The majority of the effects of the mediating and control variables do not differ from previous models, which implies that the findings are robust. Only the mediating effect of subjective health changes from positive and significant to a slightly positive and non-significant effect.

## 4. Conclusions

With this contribution we aimed to gain insight in the relationship between suffering from celiac disease or NCGS and informal social capital. We enriched previous

research in several ways. First, previous studies took into account perceived social restrictions considering celiac disease and the gluten free diet, while in this research, we looked at the actual amount of social contacts. Second, we compared celiac disease or NCGS patients with a healthy control group and made an explicit distinction between having celiac disease or NCGS, which has not been done before.

By making use of the membership file of the Dutch Celiac Association to send out a questionnaire, we gathered high quality data to answer our research questions.

Certain resources (for example income or education) can positively influence social capital [10,11]. In this research, we argued that suffering from celiac disease or NCGS can be seen as a lack of resources and thus a constraint in the formation and maintenance of social capital. Furthermore, we investigated whether differences in informal social capital between the healthy subpopulation and people who suffer from celiac disease or NCGS could be explained by several factors related to health, namely feelings of depression, physical symptoms, poor subjective health and having another chronic condition.

It appears that people who suffer from celiac disease or NCGS indeed have less informal social capital than a healthy subpopulation. The fact that celiac disease and NCGS patients have less social contacts can be explained by several characteristics, i.e., depression, poor subjective health and having another chronic condition. However, these factors do not explain the initial relationship between

suffering from celiac disease or NCGS and informal social capital completely. It appears that several demographic variables play a more important role, since these factors do reduce the effects of having celiac disease or NCGS to non-significance.

On the basis of the outcomes, we argue that celiac disease or NCGS can indeed be seen as a constraint regarding informal social capital. The described relationships of celiac disease or NCGS with the formation of informal social capital and the effects of depression, subjective health and other chronic illnesses seem to hold and should be taken into account as risk factors for social isolation in clinical practice. However, the fact that differences in social capital are reduced completely by demographic variables is very important and shows that gender, age and household characteristics (marital status and having children) play a large role as well.

Our comparison with a healthy control group proved to be fruitful, but the methodological and analytical strategy was challenging. A sample of healthy people which is not, or less, dependent on the group of people who suffer from celiac disease or NCGS is something to consider in future research.

To conclude, we showed that not only perceived social restrictions are important to take into account as previous research demonstrated, but that the actual amount of social contacts of people who suffer from celiac disease or NCGS can be deprived as well. Although most of the differences in informal social capital between people who suffer from celiac disease or NCGS and the healthy control group can be explained by demographic characteristics, professionals and future research should take into account that celiac disease or NCGS patients who suffer from depression, a poor subjective health or several chronic conditions can be at risk for having a smaller amount of social capital.

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We want to thank the Dutch Celiac Association for their aid with regard to the data collection of this research. Furthermore, we especially thank all respondents for filling in our questionnaire.

## Statement of Competing Interests

The data collection for this research has been fulfilled in collaboration with the Dutch Celiac Association. The Dutch Celiac Association is the Dutch patient association for people who suffer from celiac disease and non-celiac gluten sensitivity. However, it was ensured that this research meets high quality standards and was not substantively influenced by other parties.

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