# Socioemotional and task-oriented helping mechanisms in an online support group for Celiac Disease patients

Bachelor Thesis – University of Twente

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Abstract English

Online support groups (OSGs) are gaining more influence in the self-therapy of diseases and distresses. Mainly, two kinds of helping mechanisms are to be found in OSGs: socioemotional and task-oriented helping mechanisms. Celiac disease (CD) is an autoimmune disorder in which it is of great importance for the patients to follow a gluten-free diet (GFD), which is difficult. Therefore, participation in an OSG could be meaningful for CD patients. But how do CD patients who are active on Facebook participate in an OSG and is there a difference between the participation on workdays and weekends? The question was answered by analyzing 930 messages of 12 days in the German Facebook-group "Zöliakie Austausch". For the analysis, the coding scheme by Finn (1999) served as a basis, because it includes socioemotional *and* task-oriented codes, which he used to analyze an OSG for people with disabilities. The members of "Zöliakie Austausch" participate by writing socioemotional and task-oriented messages, of which the task-oriented messages are written more frequently. In their messages, the group members provide and ask information about gluten-free products, places to go to, recipes and medical topics. But the group members also share personal stories and express feelings. In addition, differences were found between participation on workdays and weekends: more negative feelings and seeking support is expressed on workdays and more positive feelings on the weekend. Especially the aspect that task-oriented messages were written more frequently, underlines that there are deficiencies in the health-care system regarding the information that patients get about this disease. In addition, the group seems to be a place for the members to share their own stories and feelings because they know that they are among like-minded. The difference between participation on workdays and weekends shows that real life has an influence on OSG-usage as well as the other way round. These results can serve as a basis for many further research opportunities, for example to analyze the effect of participation on the quality of life of the members or the adherence to the GFD. If positive effects of participating will be proven, such a group could help every CD patient.

Abstract Dutch

Online zelfhelp groepen (OZG) krijgen steeds meer invloed in de zelftherapie van ziekten en noden. Hoofdzakelijk, twee soorten help mechanismen zijn te vinden in OZG: sociaal-emotionele en taakgerichte help mechanismen. Coeliakie is een auto-immuunziekte waarbij het van groot belang is voor de patiënt een glutenvrij dieet (GVD) te volgen, wat erg moeilijk is. Daarom is deelname aan OZG zinvol voor de Coeliakie patiënten. Maar hoe participeren coelikaie patiënten die actief zijn op Facebook in een OZG en is er een verschil tussen de participatie op werkdagen en in het weekend? Deze vraag werd beantwoord door het analyseren van 930 berichten van 12 dagen in de Duitse Facebook-groep "Zöliakie Austausch". Het codeerschema door Finn (1999) diende als basis voor de analyse, omdat het sociaal-emotionele *en* taak-gerichte codes bevat. De leden van "Zöliakie Austausch" nemen deel aan de groep door het schrijven van sociaal-emotionele en taakgerichte berichten, waarvan de taakgerichten een groter deel uitmaken. In hun berichten geven of vragen de leden informatie over glutenvrije producten, plaatsen om naar toe te gaan, recepten en medische onderwerpen. Maar de leden van de groep delen ook persoonllijke verhalen en uiten hun gevoelens. Daarnaast werden verschillen gevonden tussen participatie op werkdagen en in het weekend: meer negatieve gevoelens en het zoeken van steun wordt uitgedrukt op werkdagen en meer positieve gevoelens in het weekend. Vooral het aspect dat taakgerichte berichten vaker worden geschreven, benadrukt dat er tekortkomingen zijn in de gezondheidszorg met betrekking tot de informatie die patiënten krijgen over deze ziekte. Daarnaast lijkt de groep een plek voor de leden te zijn om hun eigen verhalen en gevoelens te delen, omdat ze weten dat ze onder gelijkgezinden zijn. Het verschil tussen participatie op werkdagen en weekend leert dat het echte leven invloed heeft op de deelname aan OZG en andersom. In verder onderzoek kan bijv. het effect van deelname op de levenskwaliteit worden geanalyseerd. Als positieve effecten van de deelname worden bewezen, kan een dergelijke groep help zijn voor elke Coeliakie patiënt.

Table of Contents

*'The first birthday of my daughter after the diagnosis. Since the advice of the nutritionist was a total disaster, I have helped myself fairly with literature – it was okay… Then, I have found this group and I can only say THANK YOU!!! The many ideas I already got here – and I finally dared to bake again. Here is a small selection of our cake buffet'*

Online support groups (OSGs) are gaining more and more importance in the self-therapy of diseases and distresses. This article is going to examine the behavior of members of an OSG on the basis of a Facebook group with the topic celiac disease. For this purpose, OSGs and their helping mechanisms are described. One example of a disease where OSGs can be effective is celiac disease, which is nowadays one of the most prevalent autoimmune disorders. On the basis of the messages of the members, the way of participating in an OSG is analyzed using a deductive and inductive approach.

## (Online) Support Groups

Cotton and Gupta (2004) found out that more and more people are relying on internet search to find health related information. Especially, people are more often using social media for health-related communications. One reason is that the use of social media may increase the feeling of social support (Wangberg et al., 2008; Idriss, Kvedar & Watson, 2009). Another reason is that the content is user-generated and in this way the information is more patient centered than on non-interactive websites (Hawn, 2009). Because of these and more reasons, there are many different peer to peer support groups to find on the internet, in form of mailing lists, chat rooms and discussion forums for nearly every kind of distress and diseases such as cancer, AIDS and chronic pain (Eysenbach, Powell, Englesakis, Rizo & Stern, 2004).

Peer to peer support groups, although existing in different forms, have several characteristics. First, they follow no treatment-protocol and have usually no leader, except a nonprofessional administrator. Second, the participation in these groups has the goal to offer relief and improve the feelings of the group members and not therapeutic changes. Third, people can join and leave the group whenever they want, because the group is open and not time-limited (Barak, Boniel-Nissim & Suler, 2008).

Online peer to peer support groups originated of face2face support groups. Both kinds of groups, online and face2face, are characterized by fostering people's general well-being (Barak et al., 2008). The greatest difference between face2face groups and OSGs is that people can access OSGs from everywhere in the world and at every time. People can participate no matter where they are as long as they have access to the internet (Finn, 1999).

They do not need to be able to leave their house or even their bed. Another advantage is the anonymity of the internet that makes it easier to participate for patients, especially for those who are suffering from stigmatizing issues such as AIDS, and who would need a greater surmounting to participate in face2face groups (Finn, 1999). Also, a great number of group members can provide a huge amount of different information (Finn, 1999).

Positive effects of social media and OSGs on coping with illnesses were also found (Klemm et al., 2003; Liebermann et al., 2003; Barak et al., 2008; Merolli, Gray & Martin-Sanchez, 2013). Klemm et al. (2003) concluded after a review of studies about online cancer support groups that in 9 of 10 studies, the groups helped the patients to cope more effectively. The main focus of these OSGs was the seeking and giving of disease-related information. Liebermann et al. (2003) found out that an electronic support group for women with breast cancer reduced depression and reactions to pain and showed the participants new possibilities for coping with the cancer. Barak, Boniel-Nissim and Suler (2008) showed in their literature review that OSGs benefit well-being, give a sense of control, self-confidence, feelings of more independence, and enhance social interactions. Benefits for psychosocial management were found by people using social media for chronic disease management, too (Merolli et al., 2013).

On the other hand, there are some disadvantages of the nature of OSGs. Merolli et al. (2013) mentioned that it is important to tailor OSGs and interventions directly to the needs of the patients. Finding the group that fits best to the needs of the people can be hard, because there are so many groups nowadays with different specializations (Barak, Boniel-Nissim, & Suler, 2008). But before the people can find the best OSG for their purpose, they need to have access to the internet, which might exclude poor and older people, and they need to be able to read and write, which excludes illiterates from participating (Galinsky et al., 1997 as cited in White & Dorman, 2001; Dickerson et al., 2000). Another disadvantage lies in the nature of online messages themself. They can easily be misinterpreted, because there are no visual and aural cues for the reader (Barak, Boniel-Nissim, & Suler, 2008). But the messages can also be meant to harass other group members, because OSGs are usually open for everyone and often unmoderated and the authors of such messages can stay fully anonymous (Barak, Boniel-Nissim, & Suler, 2008). Another issue is the provided information, which can be completely wrong, because of the lack of professionals in the group (Dickerson, 2000).

Nowadays, OSGs are to be found everywhere. In the last few years, a trend has surfaced to use social media platforms such as Facebook and Tumblr to communicate about different forms of distress. For example, Gonzales-Polledo and Tarr (2014) made a content

analysis on Tumblr and Flickr on shared content regarding chronic pain. They concluded that people use Flickr to make the pain experience visible and search for empathy, and people use Tumblr to build up networks and support communities (Gonzales-Polledo & Tarr, 2014). Greene, Choudhry, Kilabuk and Shrank (2011) did a qualitative evaluation of the communication of patients with diabetes with Facebook. They found out that not only the diabetes patients but also their family members and friends use Facebook for different actions, such as sharing personal clinical information, asking disease specific questions, for example about guidance and feedback, and receiving emotional support (Greene et al., 2011).

It is striking that there are mainly two sites of helping mechanisms of OSGs und social media platforms. On the one hand there is social support and emotions. A lot of people are participating in OSGs to get a feeling of universality, and to enhance emotional support and social interactions (Greene et al., 2011; Barak, Boniel-Nissim and Suler, 2008; Finn, 1999). On the other hand there are more task-oriented objectives. These include the sharing of and asking for disease-related information, guidance, problem solving, and feedback (Greene et al., 2011; Klemm et al., 2003; Finn, 1999). Finn (1999) conducted a study, where he analyzed an OSG for people with disabilities. He developed the category system on the basis of the Social Support Behavior Code by Cutrona and Suhr (as cited in Mo & Coulson, 2008) and of the therapeutic self-help group mechanisms which he found in the group work literature (Finn, 1999). Afterwards, he coded the messages into two categories (socioemotional messages and task-oriented messages) and found out that the messages were equally divided into the two categories. The highest amount of messages fell into the subcategories "provides support and empathy" (socioemotional), "provides information" (task-oriented) and "problem solving" (task-oriented). Only a few messages fell in the subcategories "damaging statements" (socioemotional), "poetry or art" (socioemotional) and "taboo topics" (socioemotional; Finn, 1999).

One example of a disease where both, socioemotional aspects and exchanging information, are important, is celiac disease (CD). The patients with CD have to rely on friends and acquaintances for disease-related information because the primary care physicians do not provide enough information. CD patients seem to be the perfect target group for OSGs.

**Case: Celiac Disease**

"Is this gluten-free?", "Can I get this without lactose?", "I am only eating what is vegan." - Nowadays, more and more people are concerned about what they are eating. Whereas some people do this voluntarily, others are forced to do so. One disease that forces people to change their eating habits is CD. In Western countries, 1% of the population has CD. This illness is

an autoimmune disorder and nowadays one of the most prevalent ones world-wide (Haider, 2010). When someone has CD, the ingestion of gluten has the consequence that the villi in the intestines get damaged which will lead to malabsorption (nutrients can no longer be received; Fasano et al., 2003; Dietrich et al., 1997). The only known therapy is a fully gluten-free diet (GFD), otherwise CD can lead to death (Haider, 2010). In the last 30 years, the number of clinical diagnoses has increased more than fivefold, but the detection ratio lies still between 1:3 to 1:5 between diagnosed and undiagnosed cases (Catassi, Gatti & Fasano, 2014).

A fully gluten-free diet does not only mean waiver of bread and pasta. In every packaged food, gluten can nowadays be an ingredient because gluten has several positive characteristics such as being a flavour enhancer and a thickener (Deutsche Zöliakie Gesellschaft e.V., 2016). To follow a GFD means that the patient has to avoid every milligram of gluten, a total of only 20 milligram per kilogram is allowed (Deutsche Zöliakie Gesellschaft e.V., 2016). Therefore, the gluten-free food is taken out of the following three main categories: naturally and unprocessed gluten-free food (e.g. raw vegetables or meat), products which are marked as gluten-free following a specific standard, and products where gluten is not indicated as one of the ingredients (Coeliac UK, 2016). In the last case, it is recommended to only eat what is listed in the lists of the Association of European Coeliac Societies (AOECS; Deutsche Zöliakie Gesellschaft e.V., 2016).

A lot of people do not adhere completely to the diet. A study in Brazil shows that more than half of the participants with CD did not follow a gluten-free diet, although they said to do so (Machado et al., 2013). A Swedish study found that only 36% of adults with CD strictly adhere to the diet (Högberg, Grodzinsky, & Stenhammar, 2009). In other studies, the percentage of being compliant with the GFD varies between 17% and 45% (Ciacci, Cirillo, Cavallaro & Mazzacca, 2002; Bardella et al., 1994; Rashid et al., 2005).

There are several reasons why it is so difficult to adhere to this diet. First of all, the people have to rely more and more on packaged food nowadays, because their lifestyles do not allow spending a lot of time in the kitchen. Also, packaged food is inexpensive and available everywhere. But, most of this packaged food is wheat-based and therefore not suitable for people with CD. Gluten-free substitutes are sometimes difficult to find and usually more expensive (Leffler et al., 2008). Another reason that increases the difficulty of a GFD is that it is difficult to participate in social events, like going to restaurants and having barbecues. Every time when other people are involved in the process of cooking, it is difficult to be sure to get a totally gluten-free meal. The same applies to traveling. Traveling is one of the aspects where CD patients have the most concerns about (Casellas et al., 2008; Leffler et

al., 2008). Psychological factors are playing a role in compliance to the GFD, too. Experiencing stress or changes in mood can make it difficult to be disciplined enough to resist gluten (Leffler et al., 2008). In addition, a GFD by adolescents can even worsen the already nutritionally unbalanced diet. Therefore, not only a GFD is important but also a healthy and balanced diet (Mariani et al., 1998) Finally, it is difficult to control if one's own diet is excluding all gluten, because laboratory test results such as blood tests of antibodies are inaccurate (Vahedi et al., 2003). The only way of knowing for sure that all gluten is excluded is to be observed by a nutritionist for several days and in several areas of life (Ciacci et al., 2002).

But still, a GFD is the only therapy for CD, so it is important for the patients to follow the diet strictly. A GFD reduces all the symptoms of CD patients (Assor et al., 2015). Thereby, it also enhances the quality of life of the patients, so that they have the same quality of life as average healthy people (Wagner et al., 2008; Nachman et al., 2010; Mustalahti et al., 2002, Ciacci et al., 2003; Kurppa, Collin, Mäki, & Kaukinen, 2011; Casellas et al., 2008). Mustalahti et al. (2002) found that the advantages of following a GFD even predominate the disadvantage of having the burden of not being able to eat everything.

It is very important to help the patients to adhere to the diet. Several studies found that adherence is better if the patient is diagnosed early in life (Högberg et al., 2009; Wagner et al., 2008), which shows that early screenings and spreading the knowledge of the disease is important. But it is not helpful for the people who already have a diagnosis. Leffler et al. (2008) conducted a study to find out factors that influence the compliance to a GFD. The most important one for adhering to the GFD is having the correct and needed information. Leffler et al. (2008) also found that there are "striking deficiencies both in the quality of information and in the level of support that patients receive from their health-care providers" (p. 6, Leffler et al., 2008), although these people should be the main source of information. Accordingly, only one-third or less of their participants have rated their primary care physicians positively (Leffler et al., 2008). Leffler et al. (2008) also discovered that patients with CD rely more on their friends and acquaintances, no matter if these people are also diagnosed with CD or not, than on their primary care physicians. This underlines the importance of social support and the mentioned remarkable deficiencies of the health sector (Leffler et al., 2008).

To summarize, it is very important to have social support and the correct information for CD patients. One way of finding both, social support and the information, independent of location and time, is participating in OSGs. They foster well-being, enhance social support and serve as an information source. An OSG could be the option for CD patients, also in

helping to adhere to the diet through providing social support and a feeling of universality and the providing of the correct and needed information. But until now, no research was conducted studying CD OSGs, although, as mentioned above, CD is one of the most prevalent autoimmune disorders. Therefore, it is important to investigate OSGs for CD patients. The German Facebook group "Zöliakie Austausch" (English: "Celiac disease exchange") serves for many patients as an OSG. To use the possible power of OSGs, it first needs to be analyzed, how the people are using it. So, how do CD patients who are active on Facebook participate in an OSG? To be able to provide an extensive answer, the content of the messages of the members of the group will be analyzed with regard to socioemotional and task-oriented helping mechanisms. Also, the question if there is a difference in participation between workdays and weekends will be answered to take an external factor in the way of using the OSG into account. In this way it can be analyzed, in which way the reality corresponds with the virtual reality and it affects.

*How do CD patients who are active on Facebook participate in an OSG?*

  - *Is there a difference in the participation between workdays and weekends?*

## Methods

### Participants

The people who were studied are members of the German Facebook group "Zöliakie Austausch", which was established 5 years ago on May 3rd 2011 by a CD patient. They all have in common that they have an interest in CD, as well being a patient with CD, as a parent with children or grandchildren with CD or they have contact to CD in their work. Members younger than 18 were excluded in this study.

The group has over 11.000 group members in Germany, Austria and Switzerland. The stated purpose of the group is to create a place for the exchange of information around the topic CD. Because of their large number, the members can get an answer quickly for every question regarding CD. Furthermore, the group is "closed" which means that only people can be members if the administrators of the group accepted the member request.

Out of 930 messages, which were read prior to analyzing, 792 were conducted by an author with a female name, 81 messages by an author with a male name, and 57 messages by an author with an ambiguous name. The content of 10 messages was not related to CD but to, for example, other diseases, such as gluten sensitivity or other food intolerances, so they were left out in the further analysis. Also two messages about organizational topics within the group were left out.

Figure 1 shows a screenshot of the Facebook group. At the top, there is a picture showing 15 ingredients which all contain gluten and which CD patients are not allowed to eat. The bottom shows the discussion page (1) of the group. Here, every group member has the opportunity to share a message, a picture or a video, ask a question or upload a file (4), and also to give an answer to the messages of other members. At "Veranstaltungen" (2) the members can have a look at events that are organized from and for members of the group, such as a visit to a restaurant. At "Dateien" (3), the members can find different files, containing information about restaurants, tips and tricks, journey reports and recipes. To have an overview over all the possibilities, every new member is personally welcomed by a message, where the rules of the group and the possibilities are shown (Appendix A).



*Figure 1*. Screenshot of the Facebook group "Zöliakie Austausch"

**Data set**

This study analyzed semi-public data, which occurred naturally and were not generated by this study. Every message conducted in the Facebook group "Zöliakie Austausch" by

members over 18 years old on one of twelve different days was used in this study. The answers to the messages were left out, because the amount of text would exceed this study (e.g. 80 messages have approximately 750 answers). Furthermore, the messages, which were conducted to welcome a new member were left out, because it is the same text for every new member on every day (see Appendix A) and because of this nature of the message, possible differences between the days cannot be deduced. The number of welcome-messages is also independent of the day because the administrators decide when an accession request will be accepted.

The chosen days were $16^{th}$, $22^{nd}$, $24^{th}$, $27^{th}$, and $30^{th}$ March 2016 and $3^{rd}$, $5^{th}$, $7^{th}$, $9^{th}$, $11^{th}$, $13^{th}$, and $15^{th}$ April 2016. These days should give an overview over the activity in the group on different kinds of days. Therefore, the days include weekend days, workdays and holidays. Because of the nature of the Facebook group, it was not possible to go back in the history of the group to take messages of other years into account.

**Procedure**

This research was ethically approved by the Ethics Commission of the University of Twente. The members of the Facebook group were not informed beforehand, but the administrators of the group were asked for their permission and informed about the study and the anonymity precautions. Authors of messages which are cited in this thesis, were asked via a personal message on Facebook for their permission to publish their message after the data was gathered. When permission was granted, the names were, nevertheless, excluded from citing.

The messages were manually copied in Microsoft Office Word 2013. They were stored including information about the gender of the author, which was generated on the basis of the name of the author. If the name was ambiguous, no gender was determined. Furthermore, a code for the date was added to each message. The cited German messages were translated, in the manner that one person translated the messages from German to English and another person translated them back to German. In this way, it was guaranteed that the translation was correct.

**Analysis**

The categories mentioned in the introduction which are divided into two main-categories, socioemotional and task-oriented helping mechanisms, serve as a basis in this article, so the coding was mostly structured and deductive. These categories (Table 1) were derived from Finn (1999), who used a coding scheme to explore the helping mechanisms and contents of OSGs for disability related issues. After reading the first 200 messages, the coding scheme was adjusted to the topics of this OSG. So, open coding was also applied to generate new

fitting codes. In this way, a deductive and an inductive approach was used to establish the coding scheme.

Table1

*Finn's Coding Scheme (1999)*

| Main-category | Subcategory | Explanation |
| --- | --- | --- |
| Socioemotional messages | Expressing feelings or catharsis | Involves expressing feelings, being self-revealing, or telling of emotional or traumatic events |
| | Providing support or empathy | Responding with helpful or comforting words, talking with someone about the emotional component of a problem or circumstance, or showing understanding of another's situation |
| | Chit Chat | General conversation between two people that emphasizes everyday talk and does not specifically address any other codes |
| | Universality | Expressing the idea that people have the same experiences or report similar experiences, circumstances, or feelings; stating that the person is "not all alone" and that others have experienced similar situations, feelings, and emotions |
| | Friendship | Expressions of friendship, discussions of making friends in the group |
| | Extra-group relationships | Discussions about interactions outside the group, including phone call, visits, "snail mail", doing things they have in common, going out for dinner, and interacting in other personal ways – outside of the electronic support group |
| | Taboo topics | Subjects, problems, or situations that generally may not be openly discussed. These are considered "private", and include |

| | | topics concerning sex, extramarital affairs, suicide, child abuse, drug use, or things for which others may place negative judgement on the person |
|---|---|---|
| | Damaging statements | Any statement in which a participant acknowledges being hurt by someone's comments on the conference or any statement that may cause hurt through verbal hostility |
| | Poetry and art | Thoughts, feelings, or emotional expressed through verses, prose, or art |
| Task-oriented messages | Asks information | Asking if others know information r facts about a specific subject, topic, disease, treatment, process, or policy |
| | Provides information | Stating or providing factual and useful information, information regarding specific problems or certain subjects |
| | Problem solving | An exchange of ideas, in which people offer specific advice or ask questions of others to solve specific problems |
| | Computer talk | Discussion about computers, modems, conferences, lurkers, problems with computers, or computer jargon used in the conversation |
| | Group cohesion | Messages that provide a sense of how members feel about the group |

While using the coding scheme, the unit of analysis was one message. Each message was coded with the codes that were the most applicable. Context information, such as the answers to the messages, were left out in the coding process. Only the information in the message was used. The messages were coded with the help of Atlas.ti.

## Results

This section is going to provide an answer to the question, how CD patients who are active on Facebook participate in an OSG, and the subquestion if there is a difference between

workdays and weekends. The way of participating was analyzed on the basis of the messages of the members. These messages showed a wide variety of contents and forms, ranging from socioemotional messages to task-oriented messages.

**Structure of the coding scheme**

Most of Finn's (1999) codes were applicable to the messages of this Facebook group. The codes and there definitions which were directly applicable in this context were the following codes for socioemotional messages: 'Providing support or empathy', 'Extra-Group Relationships', and the following codes for task-oriented messages: 'Problem Solving', and 'Group Cohesion'. But some of Finn's (1999) codes also needed to be adapted to this group. These include one code for socioemotional messages, 'Expressing Feelings', where two sub-codes were generated, one for positive emotions and one for negative emotions and two codes for task-oriented messages, namely 'Asks Information', and 'Provides Information'. These codes were subdivided in five different topics for which the group members were asking or providing information most frequently: medical topics, places, products, recipes and something else. New codes that were generated with open coding because they were missing in Finn's (1999) coding scheme were 'Personal Story', and 'Seeking Support or Empathy' in the group of the codes for socioemotional messages and 'Commercial Background' in the group of codes for task-oriented messages (for definitions, see Table 2). Seven codes from Finn (1999) were not needed at all while coding because their topics were not relevant in this group. These include 'Universality', 'Chit Chat', 'Friendship', 'Taboo Topics', 'Damaging Statements', and 'Poetry and Art' of the codes for the socioemotional messages and the code 'Computer Talk' of the codes for the task-oriented messages (for definitions, see Table 1). In Table 2, an overview is provided about the number of times a code was used.

Table 2:
*Overview codes with definition, frequency in total and mean amount and percentage per workday and day on weekend*

| Coding category | Definition | Total | Weekend: mean amount per day (percentage of all used codes on weekends) | Workdays: mean per day (percentage of all used codes on workdays) |
|---|---|---|---|---|
| **Socioemotional messages TOTAL** | | **622** | **41.75 (35.76%)** | **36.13 (34.73%)** |
| Expressing Feelings | Involves expressing feelings, being self-revealing, or telling of emotional or traumatic events | 208 | 18.5 (15.45%) | 16.75 (15.99%) |
| - *Negative Feelings* | *Expressing negative feelings* | 47 | 2 (1.67%) | 4.88 (4.65%) |

| | | | | |
|---|---|---|---|---|
| - *Positive Feelings* | *Expressing positive feelings* | 161 | 16.5 (13.78%) | 11.88 (11.34%) |
| *Personal Story* | *Sharing one's own background, such as one's experiences in the past or plans for the future, for example to illustrate why questions are asked* | 343 | 33.25 (27.77%) | 26.25 (25.06%) |
| Providing Support/Empathy | Responding with helpful or comforting words, talking with someone about the emotional component of a problem or circumstance, or showing understanding of another's situation | 9 | 0.75 (0.63%) | 0.75 (0.72%) |
| *Seeking Support/Empathy* | *Seeking helpful and comforting words, sharing feelings of helplessness or frustration* | 25 | 1.25 (1.04%) | 2.5 (2.39%) |
| Extra-Group Relationship | Discussions about interactions outside the group, including phone call, visits, "snail mail", doing things they have in common, going out for dinner, and interacting in other personal ways – outside of the electronic support group | 37 | 3.75 (3.13%) | 2.75 (2.63%) |
| **Task-oriented messages TOTAL** | | **1053** | **75 (64.23%)** | **68.38 (65.27%)** |
| Asks Information | Asking if others know information or facts about a specific subject, topic, disease, treatment, process, or policy | 384 | 23 (19.21%) | 31.25 (29.83%) |
| - *medical topics* | | 61 | 4.5 (3.76%) | 5.38 (5.13%) |
| - *places* | | 104 | 6 (5.01%) | 10 (9.55%) |
| - *products* | | 129 | 7.25 (6.05%) | 12.5 (11.93%) |
| - *recipes* | | 67 | 4 (3.34%) | 6.38 (6.09%) |
| - *else* | | 23 | 3.5 (2.92%) | 1.13 (1.07%) |
| Provides Information | Stating or providing factual and useful information, information regarding specific problems or certain subjects | 620 | 51 (42.59%) | 35.75 (34.13%) |
| - *medical topics* | | 8 | 1 (0.84%) | 0.5 (0.48%) |
| - *places* | | 214 | 18.75 (15.66%) | 17.38 (16.59%) |
| - *products* | | 168 | 14 (11.69%) | 14 (13.37%) |
| - *recipes* | | 187 | 25 (20.88%) | 10.88 (10.38%) |
| - *else* | | 43 | 1.75 (1.46%) | 4.5 (4.3%) |
| Problem Solving | An exchange of ideas, in which people offer specific advice or ask questions of others to solve specific problems | 20 | 2.25 (1.88%) | 1.38 (1.31%) |
| Group Cohesion | Messages that provide a sense of how members feel about the group | 9 | 0.5 (0.42%) | 0.88 (0.84%) |

| | | | | |
|---|---|---|---|---|
| *Commercial Background* | *Sharing commercials by business men about gluten-free products or wanting to sell something by a normal group member* | 20 | 1.25 (1.04%) | 1.38 (1.31%) |
| TOTAL NUMBER OF MESSAGES: | | 1675 | 116.75 | 104.5 |

*Notes.* New codes are written in italic.

**Helping mechanisms in more detail**

In the following, an overview is provided about the topics that concerned the group members on the basis of the coding scheme. As described in the literature, both kinds of messages, socioemotional and task-oriented, were present. In general, the group members wrote both kinds of messages frequently, socioemotional and task-oriented, although codes for socioemotional messages were only 37.13% of all used codes.

  **Socioemotional messages.** On the one hand there were the socioemotional messages. In this category were the codes 'Expressing Positive Feelings', 'Expressing Negative Feelings', 'Personal Story', 'Providing Support or Empathy', 'Seeking Support or Empathy', and 'Extra-Group Relationship'. The first two codes contained the feelings that were expressed in the message, the positive ones and the negative ones ('Expressing Positive Feelings', 'Expressing Negative Feelings'), which were triggered off by an emotional event regarding CD or the GFD. The group members expressed more than three times more positive feelings (161 times) than they expressed negative ones (47 times). For example, the members shared their feelings when they got positive feedback for their diet: "After five months of change to gluten-free, the antibodies and the mucous membrane are almost normal again. Everything is back in the norm with my baby. I am so happy right now". But they also shared their feelings when they were disappointed, for example:

> Again, a good example to always read the ingredients list! Indeed, one year is lying in between but anyhow. Aldi has these Amarettini once in a year. The first package is from last year and the second one is from this year. Had been so happily looking forward to this

The members of the group are not only often expressing their feelings, they are frequently sharing personal stories or information ('Personal Story'):

> I just watched 'Abenteuer Leben' [a German TV-show] on Kabel 1… normal bullshit… and POW, Parma ham is rubbed with a paste of lard and flour to seal up parts that are not covered by rind… I absolutely need to search for hints on the package in the store.

These personal stories were as well experiences in their everyday life, as sharing their own information (e.g. own way to the diagnosis), as plans for the day or the future, such as:

Hello. I am going to walk on the Camino de Santiago by the end of June until mid-July. From Porto (Portugal) to Cape Finisterre (westernmost point of Spain). Last time I walked the Camino de Santiago, I took a lot of crispbread with me, but I actually want to dispense with every unnecessary kilo. I want to cancel the tour under no circumstances. Has someone advice, where I can get something there.

Furthermore, the members of the group were seeking (25 times) and providing (9 times) support or empathy. This included seeking helpful or comforting words:
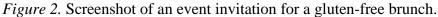
Oh man, my boyfriend and his friends want to go eat sushi. And at the end, I am going to sit next to them and watch them. Earlier, I got the answer of the shop that the vinegar for the sushi is containing wheat…,

providing helpful or comforting words, help through actions and showing understanding of another's situation:

What a nice online shop, which was introduced on the blog. I wish [name] for his young company with young ideas lots of success and I will definitely try it. Thumbs up for the courage to start something on his own. Good luck, [name].

The last part of the socioemotional messages included all messages that dealt with real life meetings or relationships ('Extra-Group Relationships'). The members of the group frequently organize offline-meetings in different cities of Germany, in this way a message of this category can also be a sharing of an event invitation created with Facebook (see figure 2). On one of the analyzed days, a great fair took place in Berlin, where a lot of members of the group were participating. So on this day, a greater number of members shared content about 'Extra-Group Relationships'.

*Figure 2.* Screenshot of an event invitation for a gluten-free brunch.

**Task-oriented messages.** On the other hand, there were the task-oriented messages. Task-oriented messages were characterized by their focus upon the exchange of information, problems in the everyday life of a CD patient, and feedback. The codes 'Asking Information' and 'Providing Information' for different topics, 'Problem Solving', 'Group Cohesion', and 'Commercial Background' belonged to that category.

The two most frequently used codes were 'Asking Information' and 'Providing Information' with their sub-categories, from which 'Providing Information' the most frequently was used (620; 'Asking Information': 384). A lot of the group members asked information about where to find what or where to eat gluten-free, so about places and products, but also about medical issues, such as laboratory values, and recipes: "Hello, has anyone a hint, how my bread is not going to be so crumbly? Does it need more liquid? It is actually rather juicy." Less frequent were questions about statutory regulations such as subsidies for the GFD or a Disabled ID card. These and other questions which did not fit in the categories 'Places', 'Products', 'Medical Topics', and 'Recipes' were put in a rest category.

In the same way, the code 'Providing Information' is set up. The members of the group are mostly providing information about where they found what, products and recipes:

"tested and approved… stainless steel shell of Weber for barbecues. Perfect for vegetables and mushrooms. And also flatbread can be prepared on the barbecue. I can imagine that you can also grill with it meat without contamination". Sometimes they are providing information about medical topics, mostly sharing new information of the DZG (German Celiac Society). There was a rest-category in the providing of information, too. Topics were lotteries or contests where gluten-free food was the winner-price and sharing links of texts of own web searches.

The other three codes were not used frequently. 'Problem Solving' includes all questions were the answer could not be a simple one. This category seems to have an overlap with the categories of asking information, but 'Problem Solving' involves more complicated issues, for example: "I could cry… I wanted to bake a bread… simple recipe by the Hammermühle package… directly following instructions… what comes out??? A collapsed, porous, slippery something 😔 The same with the 2. try… What am I doing wrong??"

Members of the group did not frequently share their opinion about the group. Only nine times, the 'Group Cohesion' was indicated in messages, such as:

> The first birthday of my daughter after the diagnosis. Since the advice of the nutritionist was a total disaster, I have helped myself fairly with literature – it was okay… Then, I have found this group and I can only say THANK YOU!!! The many ideas I already got here – and I finally dared to bake again. Here is a small selection of our cake buffet.

Furthermore, the members of the group shared 20 times a message with a commercial background. Partly, businessmen shared commercials for new products, partly CD patients wanted to sell products which they did not like to other group members: "The glutyfreeman has found something new for you and directly stored in www.glutyfreeshop.de. 2,99€ for 7 Cookies and think of your discount code of luscious 20%".

**Co-occurrence of codes.** It was typical of most of the messages that the message, so the unit of analysis, could be coded by a code of both main-categories. Especially, the socioemotional codes 'Expressing Feelings' and 'Personal Story' were frequently co-occurring with codes of the task-oriented category (193 times, and 341 times). So, the messages have frequently the form of a narrative, wherein the function is embedded of asking or providing information. Rarely a question was asked without introducing the background of the question, or information, especially about restaurants and recipes, was rarely provided without expressing feelings or telling the story behind it, for example the citation, "Hello, I

wanted to ask if somebody knows a gluten-free restaurant near Coburg. Only Steak and French Fries is slowly getting on my nerves", was coded with the codes 'Negative Feelings' and 'Asks Information – Places'. In general, 'Negative Feelings' are more often co-occurring with 'Asks Information', especially about medical topics, and 'Positive Feelings' are very frequently co-occurring with 'Provides Information', especially about recipes and places, but both codes were also frequently co-occurring with 'Personal Story'.

   **Weekend versus Workdays.** Although, on the weekend and on weekdays there is a slight difference in the mean amount of messages (84.25 and 74.5) and codes (119.75 and 104.75), the distribution on the main categories socioemotional messages (35.76% and 34.73 %) and task-oriented messages (64.23% and 65.28 %) is approximately the same. A greater difference is to be found in the different subcategories (see table 2).

   On workdays, more than twice as many members of the group expressed negative feelings and looked for support in their messages than on the weekend. Positive feelings were more often expressed on the weekend than on workdays and messages about real life meetings were also more often created on weekends. Besides, the members of the group were more frequently providing information on the weekend and more frequently asking for information on workdays. In the subcategories of the codes 'Asking Information' and 'Providing Information' differences were also noticeable. Nearly three times as much as on workdays, other information was asked on weekends. In addition, twice as much information about recipes and medical topics was provided on the weekend than on workdays. On the other hand, information about places and products was twice as much asked for on workdays and information that belonged into the rest-subcategory was twice as much provided on workdays than on weekends. Also, information about recipes was more often asked on workdays.

## Discussion

As expected, both kinds of helping mechanisms, socioemotional and task-oriented, are present in the Facebook group "Zöliakie Austausch". So, the short answer to the mainquestion, "how do CD patients who are active on Facebook participate in an OSG?" is that they are using the group for socioemotional and task-oriented purposes. In this specific group, more task-oriented messages are written than socioemotional ones. A possible reason for this is that CD patients do not get enough disease related information from their health-care providers (Leffler et al., 2008). They need to get the information elsewhere and so they count on the information they are receiving from family and friends (Leffler et al., 2008). Using this group seems therefore to be a substitute for the lack of information by the health-care system.

The amount of messages in comparison to the number of group members corresponds to results of a study by Nonnecke and Preece (2000). They found that the mean level of active participation in online groups is 10 %, but in health-support groups, the mean level is 54%. They defined lurking (not actively participating) group members as members who share zero messages in 12 weeks. The highest possible rate of active participation in this group is according to a statistical projection 59%, so slightly higher than the mean by Nonneke and Preece (2000). When the answers to the messages are taken into account, too, the highest possible amount of participation is even 600% (so 6 messages/answers per person in 12 weeks). This underlines the liveliness in this Facebook group and the importance of the group to the members.

Mainly, the group members use the group for four reasons: 'Providing Information', 'Asking Information', sharing a 'Personal Story', and 'Expressing Feelings'. The group is meant to be a place for the exchange of information, so the fact that 'Providing Information' and 'Asking Information' are frequently present, perfectly makes sense. But it is interesting that more information is provided than asked. The categories 'Providing Information' and 'Expressing Feelings' are also one of the three most used codes in Finn's (1999) study, where he analyzed an online group for disabled people in a similar way as this research analyzes the group for CD patients. The third most used code in Finn's study is 'Providing Support or Empathy' (Finn, 1999). But support or empathy is not often provided in the messages of the group members, but far more often in the reactions to the messages, which are not analyzed in the context of this study. Without the reactions to the messages, the group appears more like a platform for individuals than like a support group. But according to Davison, Pennebaker and Dickerson (2000), it is already helpful for the group members to share their experiences and build a collective wisdom, which clearly does happen in this group, even if only the messages without the answers are considered.

That it is important to the group members to share their personal stories and their feelings, can have several reasons. Firstly, by sharing their own stories the members of the group have the opportunity to get a feeling of universality because others may have gone through the same story (Finn, 1999). Secondly, the sharing of their own experiences or future plans and expressing feelings underlines that the group is more than just a place for objective information exchange. The group is a social platform where a lot of companions come together to support each other. Thirdly, sharing your own story and feelings can have a therapeutic effect on the author. According to Høybye, Johansen and Tjørnhøj-Thomsen (2005) story telling can "breach the social isolation" (p.217) that is experienced because of

having a disease. They analyzed a group for women with breast cancer and found that story telling can have an effect of empowerment on the teller and the audience, which means in their case that the patients increase their personal strength through social support (Høybye et al., 2005). Finally, that the members expressed more positive feelings than negative ones can be an evidence for a good quality of life which is, according to literature, as good with a GFD as it is in healthy people (Wagner et al., 2008).

Some of the categories and helping mechanisms that are present in the study of Finn (1999) are not present in this group. The members of the group are not writing about a possible feeling of 'Universality', 'Friendship', 'Taboo Topics', 'Damaging Statements', 'Poetry and Art', and 'Computer Talk'. 'Universality' is already expressed in the slogan of the group: "Wir sind viele!" (in English: "We are many!") and it can be expected that the members do experience this feeling, but without commenting on it directly unless asked. This corresponds with findings in Finn's (1999) study. Furthermore, it can be assumed that the lack of messages regarding 'Friendship' and 'Damaging Statements' is dependent of the structure and kind of the group. The group members usually write messages that are addressed to everyone else in the group, so there are usually no signs of 'Friendship' between group members no general pieces of conversation between two members ('Chit Chat'), and therefore also no 'Damaging Statements'. These two categories are more represented when the answers to the messages are included in the analysis, because there, the messages are more personal and therefore signs of friendship or damaging statements are mentioned more frequently. In addition, when the group members are planning to meet in real life, it belongs to the category of 'Extra-Group Relationship'. The other categories, 'Taboo Topics', 'Poetry and Art', and 'Computer Talk', are just very rarely mentioned in the group, so they were not part of the messages of the analyzed days. A 'Taboo Topic' in this group-specific context is mainly that someone does not take the GFD serious enough and even tries to convince others to do the same. In such cases, the administrators intervene and close the post with an official statement. 'Poetry and Art' is sometimes to find, when for example a group member shares a self-made poem about the GFD or someone shares a humorous picture such as the one on the front page. Further research could include the answers to the messages, because it seems that there are more socioemotional messages like 'Providing Support or Empathy', 'Friendship' and even 'Damaging Statements' to be found. It is needed to analyze these answers to the messages, too, because otherwise an important part of the usage pattern is not noticed. But this needs to be done in a larger study, with more researchers or with an automated system, because the amount of text would nearly be ten times as much per day as it is without the answers.

Just as there are categories that are not represented in the Facebook group in comparison with Finn's (1999) study, there are also categories that are represented in this group but not in Finn's (1999). 'Personal Story', one of the four most frequent categories, is such a new category as well as 'Seeking Support or Empathy' and 'Commercial Background'. 'Seeking Support or Empathy' comes forward in the way that some messages are written: desperately and helplessly. But the category is not represented often. 'Commercial Background' is a topic that seems to be typical of this kind of disease and is therefore not often present in other OSGs. Gluten-free products are more expensive than their gluten-containing alternatives and sometimes difficult to find (Lee, Ng, Zivin & Green, 2007), therefore, a lot of people try to make money with them. The people in the group profit by having members that make special offers for the group members in their restaurants and shops. So, the category 'Commercial Background' was necessary.

Furthermore, the categories 'Providing Information' and 'Asking Information' are subdivided into subcategories to gain an overview over the content topics of concern in this Facebook group. Three topics are addressed the most frequently: gluten-free products, places and recipes. As described in the introduction, CD patients are restricted in what they are able to eat (Coeliac UK, 2016). Furthermore, gluten-free products are sometimes difficult to find (Lee et al., 2007), so it is obvious that CD patients need to have information about the products to make the nourishment easier. According to Casellas et al. (2008) and Leffler et al. (2008), traveling is one of the most concerning aspects for CD patients, as well as participating in social events like going to a restaurant (Leffler et al., 2008). This is underlined by the frequency of messages about places. That the CD patients are also interested in recipes underlines the fact that most packaged food is wheat-based (Leffler et al., 2008), and they therefore need to cook and bake their own food. Questions about medical topics are also frequently asked, which underlines the lack of information provided by the health-care system (Leffler et al, 2008). But simultaneously, this raises the question to what extent the shared (medical) information are correct, because anyone in this group is able to write an answer to medical questions or to provide alleged correct medical information, independently of the own background. According to Dickerson (2000), this is one of the major disadvantages of OSGs. Further research could begin with examining the provided information in this group and to check if it is scientifically proven.

Codes are also frequently co-occurring with each other. Especially, asking and providing information are often embedded in a narrative or expressed with feelings. This shows that it is important for the members to socialize with each, otherwise they would write

their questions or information more objectively. The messages that are coded with 'Personal Story' are also interesting material for possible further research. It would be interesting to analyze in which way writing about your own experiences can help CD patients to cope with their disease or to give them a feeling of universality.

To get a more detailed overview over how CD patients who are active on Facebook participate in an OSG, a subquestion was analyzed: "Is there a difference in the participation between workdays and weekends?" There are only small differences in the number of codes and messages. Striking differences are to be found in 'Expressing Feelings' and 'Seeking Support or Empathy': more negative feelings are expressed and more support is sought on workdays, simultaneously, more positive feelings are expressed on the weekend. According to Leffler et al. (2008), it can be difficult to resist gluten while experiencing stress and stress is usually more present on workdays (Muaremi, Arnrich & Tröster, 2013). This could be an explanation for the higher amount of 'Expressing Negative Feelings' and 'Seeking Support or Empathy' on workdays. All these differences show that the real life has an influence on how the CD-patients participate in the group. But it is also the other way round. This can be seen in the number of messages concerning 'Extra-Group Relationship' and real life meetings, which is also higher on weekends because these meetings take sometimes place with group members from all over Germany.

This study provides an overview of the way, CD patients who are active on Facebook participate in an OSG. But these findings should be seen in the context of the strong and weak points of this study. It is a strong point that this study tries to provide an overview by choosing different days and kind of days to analyze, because the results show that there are differences in the participation on different kinds of days. It was only possible to analyze days that were recent. This is a disadvantage of Facebook research, because Facebook provides no opportunity to go back in time, except by manually scrolling down all other messages. Another strong point is the comparison between workdays and weekdays, which adds value to this study because no other study did this comparison up to now. The use of the coding scheme by Finn (1999) is also a strong point, because it is a coding scheme that does not only provide codes for socioemotional helping mechanisms, as many other coding schemes do (e.g. the Social Support Behavior Code by Cutrona and Suhr, as cited in Mo & Coulson, 2008), but it takes also task-oriented helping mechanisms into account, and it provides the opportunity to compare the group that was subject of the study by Finn with this Facebook group.

Nevertheless, it is a weak point that the findings are only limited generalizable. The ecological validity is limited to similar groups, for example, the groups need to have a

discussion board. In addition, not every disease or distress has such a great need for task-oriented messages as CD has. To improve the ecological validity, further research needs to be done with different groups and different diseases or distresses. Another weak point is the fact that there is no proof for possible positive effects of participation in the group. It can only be assumed on the basis of what the members are writing that they enjoy participating and benefit from it. Further research could analyze the effects of participating by the means of a comparison between the quality of life or the degree of following the GFD of people who participate and people who do not participate in the group. In addition, further research could also concentrate on the code 'Universality' by analyzing the need of the members to feel universality and a way to raise this feeling under the members of the group. That universality is important for the group members is shown in the slogan of the group ("We are many!").

A recommendation that can be made on the basis of the results is that the health-care system could use the power of OSGs to enhance the own quality of provided help for CD patients by participating in those groups. The health-care system can find a lot of information about the needs of the CD patients in this kind of groups. On the other side, the members of these groups could profit by validated expert information. But this participation of health-care providers is only conditionally possible, because the members of the group should not get a feeling of inhibition or being controlled.

**Conclusion**

OSGs are gaining more influence in the self-therapy of diseases and distresses. CD is a disease in which it is of great importance for the patients to follow a GFD, but primary care physicians are not providing enough education to do that. This is one of many reasons, why participation in OSGs is meaningful for CD patients, because the group is a place where they can get the necessary information. Although, this study lacks generalizability and proof for positive effects of the group, it still gives a detailed overview over how CD patients who are active on Facebook participate in OSGs.

The members participate by writing socioemotional and task-oriented messages, of which the task-oriented messages are written more frequently. In their messages, the group members, who are mostly CD patients themselves, provide and ask information about gluten-free products, places to go to, recipes and medical topics. Especially the last aspect underlines the deficiencies in the health-care system regarding this disease. But the group members are also sharing personal stories and expressing feelings, because the group is a place where these stories and feelings will be heard. Without taking into account what the members of the group react to the messages, the group seems more like a platform for individual experiences than a

support group. In addition, this study analyzed differences between participation on workdays and weekends, which shows the influence of real life on the participation of the members as well as the role of the participation in the group on the real life of the group members.

These findings are important, because until now, no study has examined OSGs for CD patients, even though they are the perfect target group for such groups, as described above. If positive effects of participating will be proven, such a group could help every CD patient. An OSG can be the additional support for adhering to the GFD that is nowadays still missing by the health-care providers.

**References**

Assor, E., Marcon, M. A., Hamilton, N., Fry, M., Cooper, T., & Mahmud, F. H. (2015). Design of a dietary intervention to assess the impact of a gluten-free diet in a population with type 1 Diabetes and Celiac Disease. *BMC gastroenterology*, 15(1), 1. doi: 10.1186/s12876-015-0413-0.

Barak, A., Boniel-Nissim, M., & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behavior*, *24*(5), 1867-1883. doi:10.1016/j.chb.2008.02.004

Bardella, M. T., Molteni, N., Prampolini, L., Giunta, A. M., Baldassarri, A. R., Morganti, D., & Bianchi, P. A. (1994). Need for follow up in coeliac disease. *Archives of disease in childhood*, 70(3), 211-213. doi:10.1136/adc.70.3.211.

Casellas, F., Rodrigo, L., Vivancos, J. L., Riestra, S., Pantiga, C., Baudet, J. S., ... & Gelabert, J. (2008). Factors that impact health-related quality of life in adults with celiac disease: A multicenter study. *World Journal of Gastroenterology*, 14(1), 46. doi: 10.3748/wjg.14.46.

Catassi, C., Gatti, S., & Fasano, A. (2014). The new epidemiology of celiac disease. *Journal of pediatric gastroenterology and nutrition*, *59*, S7-S9. doi: 10.1097/01.mpg.0000450393.23156.59.

Ciacci, C., D'agate, C., De Rosa, A., Franzese, C., Errichiello, S., Gasperi, V., ... & Greco, L. (2003). Self-rated quality of life in celiac disease. *Digestive diseases and sciences*, 48(11), 2216-2220. Retrieved from: http://sfx.utwente.nl:3210/prod?sid=google&auinit=C&aulast=Ciacci&atitle=Self-rated+quality+of+life+in+celiac+disease&id=doi:10.1023/B:DDAS.0000004530.11738.a2&title=Digestive+Diseases+and+Sciences&volume=48&issue=11&date=2003&spage=2216&issn=0163-2116

Ciacci, C., Cirillo, M., Cavallaro, R., & Mazzacca, G. (2002). Long-term follow-up of celiac adults on gluten-free diet: prevalence and correlates of intestinal damage. *Digestion*, 66(3), 178-185. doi:10.1159/000066757.

Coeliac UK (2016, January 8). The gluten-free diet. Retrieved from https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/gf-diet/

Cotten, S. R., & Gupta, S. S. (2004). Characteristics of online and offline health information seekers and factors that discriminate between them. *Social science & medicine*, 59(9), 1795-1806. doi:10.1016/j.socscimed.2004.02.020.

Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist*, 55(2), 205. doi: 10.1037//0003-066X.55.2.205

Dieterich, W., Ehnis, T., Bauer, M., Donner, P., Volta, U., Riecken, E. O., & Schuppan, D. (1997). Identification of tissue transglutaminase as the autoantigen of celiac disease. *Nature medicine*, *3*(7), 797-801. doi: 10.1038/nm0797-797.

Deutsche Zöliakie Gesellschaft e.V. (2016, February 28). Folgende Produkte können Gluten enthalten, müssen es aber nicht! Retrieved from http://www.dzg-online.de/hier-kann-gluten-enthalten-sein.30.0.html

Dickerson, S. S., Flaig, D. M., & Kennedy, M. C. (2000). Therapeutic connection: help seeking on the Internet for persons with implantable cardioverter defibrillators. *Heart & Lung: The Journal of Acute and Critical Care*, *29*(4), 248-255. doi: http://dx.doi.org/10.1067/mhl.2000.108326

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *Bmj*, *328*(7449), 1166. doi:10.1136/bmj.328.7449.1166

Fasano, A., Berti, I., Gerarduzzi, T., Not, T., Colletti, R. B., Drago, S., …& Pietzak, M. (2003). Prevalence of celiac disease in at-risk and not-at-risk groups in the United States: a large multicenter study. *Archives of internal medicine*, *163*(3), 286-292. doi:10.1001/archinte.163.3.286.

Finn, J. (1999). An exploration of helping processes in an online self-help group focusing on issues of disability. *Health & Social Work*, *24*(3), 220-231. doi: 10.1093/hsw/24.3.220.

Gonzalez-Polledo, E., & Tarr, J. (2014). The thing about pain: The remaking of illness narratives in chronic pain expressions on social media. *New Media & Society*, 1461444814560126. doi: 10.1177/1461444814560126

Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. H. (2011). Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. *Journal of general internal medicine*, *26*(3), 287-292. doi: 10.1007/s11606-010-1526-3

Haider, G. (2010). *Belastungen und Entlastungsstrategien von an Zöliakie erkrankten Erwachsenen nach der Diagnosestellung* (Doctoral dissertation, uniwien). Retrieved from: http://othes.univie.ac.at/9389/1/2010-04-19_9751487.pdf

Hawn, C. (2009). Take two aspirin and tweet me in the morning: how Twitter, Facebook, and other social media are reshaping health care. *Health affairs*, 28(2), 361-368. doi: 10.1377/hlthaff.28.2.361

Högberg, L., Grodzinsky, E., & Stenhammar, L. (2009). Better dietary compliance in patients with coeliac disease diagnosed in early childhood. *Scandinavian journal of gastroenterology*. doi:10.1080/00365520310003318

Høybye, M. T., Johansen, C., & Tjørnhøj-Thomsen, T. (2005). Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho‑Oncology*, 14(3), 211-220. doi: 10.1002/pon.837

Idriss, S. Z., Kvedar, J. C., & Watson, A. J. (2009). The role of online support communities: benefits of expanded social networks to patients with psoriasis. *Archives of Dermatology*, 145(1), 46-51. doi:10.1001/archdermatol.2008.529.

Klemm, P., Bunnell, D., Cullen, M., Soneji, R., Gibbons, P., & Holecek, A. (2003). Online cancer support groups: a review of the research literature. *Computers Informatics Nursing*, *21*(3), 136-142. Retrieved from: http://sfx.utwente.nl:3210/prod?sid=google&auinit=P&aulast=Klemm&atitle=Online+cancer+support+groups:+a+review+of+the+research+literature&id=pmid:12792194

Kurppa, K., Collin, P., Mäki, M., & Kaukinen, K. (2011). Celiac disease and health-related quality of life. *Expert review of gastroenterology & hepatology*, 5(1), 83-90. doi:10.1586/egh.10.81.

Lee, A. R., Ng, D. L., Zivin, J., & Green, P. H. R. (2007). Economic burden of a gluten-free diet. *Journal of human Nutrition and Dietetics*, 20(5), 423-430. doi:10.1111/j.1365-277X.2007.00763.x

Leffler, D. A., Edwards-George, J., Dennis, M., Schuppan, D., Cook, F., Franko, D. L., ... & Kelly, C. P. (2008). Factors that influence adherence to a gluten-free diet in adults with celiac disease. *Digestive diseases and sciences*, 53(6), 1573-1581. doi:10.1007/s10620-007-0055-3.

Lieberman, M. A., Golant, M., Giese-Davis, J., Winzlenberg, A., Benjamin, H., Humphreys, K., ... & Spiegel, D. (2003). Electronic support groups for breast carcinoma. *Cancer*, *97*(4), 920-925. doi: 10.1002/cncr.11145

Machado, J., Gandolfi, L., Almeida, F. C., Almeida, L. M., Zandonadi, R. P., & Pratesi, R. (2013). Gluten-free dietary compliance in Brazilian celiac patients: questionnaire versus serological test. *Nutr. clin. diet. hosp*, 33, 46-49. doi: 10.12873/332gluten.

Mariani, P., Viti, M. G., Montouri, M., La Vecchia, A., Cipolletta, E., Calvani, L., & Bonamico, M. (1998). The gluten-free diet: a nutritional risk factor for adolescents with celiac disease?. *Journal of pediatric gastroenterology and nutrition*, 27(5), 519-523. Retrieved from: http://ovidsp.tx.ovid.com/sp-

3.18.0b/ovidweb.cgi?QS2=434f4e1a73d37e8ce9039fe5cc4f834c9a475c5824b7e7e0877d2
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7f5a2d61da301e146c078a5b9e80d5c36cba1ede5663938bda43ecd39f8cc6

Merolli, M., Gray, K., & Martin-Sanchez, F. (2013). Health outcomes and related effects of
using social media in chronic disease management: A literature review and analysis of
affordances. *Journal of Biomedical Informatics*, *46*(6), 957-969.
doi:10.1016/j.jbi.2013.04.010

Mo, P. K., & Coulson, N. S. (2008). Exploring the communication of social support within
virtual communities: a content analysis of messages posted to an online HIV/AIDS support
group. *Cyberpsychology & behavior*, *11*(3), 371-374. doi:10.1089/cpb.2007.0118.

Muaremi, A., Arnrich, B., & Tröster, G. (2013). Towards measuring stress with smartphones
and wearable devices during workday and sleep. *BioNanoScience*, *3*(2), 172-183.
Doi:10.1007/s12668-013-0089-2

Mustalahti, K., Lohiniemi, S., Collin, P., Vuolteenaho, N., Laippala, P., & Maki, M. (2002).
Gluten-free diet and quality of life in patients with screen-detected celiac disease. *Effective
clinical practice*, 5(3), 105-113. Retrieved from:
http://ecp.acponline.org/mayjun02/mustalahti.pdf?referer=www.clickfind.com.au

Nachman, F., del Campo, M. P., González, A., Corzo, L., Vázquez, H., Sfoggia, C., ... &
Mauriño, E. (2010). Long-term deterioration of quality of life in adult patients with celiac
disease is associated with treatment noncompliance. *Digestive and Liver Disease*, 42(10),
685-691. doi:10.1016/j.dld.2010.03.004.

Nonnecke, B., & Preece, J. (2000, April). Lurker demographics: Counting the silent. In
*Proceedings of the SIGCHI conference on Human Factors in Computing Systems* (pp. 73-
80). ACM. doi: 10.1145/332040.332409

Rashid, M., Cranney, A., Zarkadas, M., Graham, I. D., Switzer, C., Case, S., ... & Butzner, J.
D. (2005). Celiac disease: evaluation of the diagnosis and dietary compliance in Canadian
children. *Pediatrics*, 116(6), e754-e759. doi: 10.1542/peds.2005-0904.

Vahedi, K., Mascart, F., Mary, J. Y., Laberenne, J. E., Bouhnik, Y., Morin, M. C., ... & Matuchansky, C. (2003). Reliability of antitransglutaminase antibodies as predictors of gluten-free diet compliance in adult celiac disease. *The American journal of gastroenterology*, 98(5), 1079-1087. doi:10.1111/j.1572-0241.2003.07284.x.

Wagner, G., Berger, G., Sinnreich, U., Grylli, V., Schober, E., Huber, W. D., & Karwautz, A. (2008). Quality of life in adolescents with treated coeliac disease: influence of compliance and age at diagnosis. *Journal of pediatric gastroenterology and nutrition*, 47(5), 555-561. doi: 10.1097/MPG.0b013e31817fcb56.

Wangberg, S. C., Andreassen, H. K., Prokosch, H. U., Santana, S. M. V., Sørensen, T., & Chronaki, C. E. (2008). Relations between Internet use, socio-economic status (SES), social support and subjective health. *Health promotion international*, 23(1), 70-77. doi: 10.1093/heapro/dam039.

White, M., & Dorman, S. M. (2001). Receiving social support online: implications for health education. *Health education research*, 16(6), 693-707. doi: 10.1093/her/16.6.693.

## Appendix

**Welcome-message**

Lieber Zöliakie-Austausch-Neuling, liebe Nadine, wir freuen uns, dass Du in unsere Gruppe gefunden hast.

Hier sind wichtige und hilfreiche Infos zum Lesen für den Start für Dich:

SEHR WICHTIG unbedingt bei Gruppeneintritt durchlesen

1. Die folgenden zwei Dateien sind für den Start sehr wichtig und erklären Dir, wie Du einfach uns sicher glutenfreie Lebensmittel erkennst:

a) Glutenfreies Basiswissen http://bit.ly/basisdatei

 b) Sicheres, glutenfreies Einkaufen mit der Liste der 15 bösen Zutaten https://www.facebook.com/notes/zöliakie-austausch/der-merkzettel-mit-den-15-bösen-zutaten/1092264134158743

2. Die FAQs der Gruppe: http://www.zoeliakie-austausch.de/faqs/

 Hier findest Du Antworten auf die häufigsten Anfängerfragen.

3. Das Handbuch mit Rabattcodes und vielen Infos. Wenn Du 1+2 verinnerlicht hast, findest Du hierzahlreiche weitere interessante Infos: http://bit.ly/zoeliakiehandbuch

4. Auf unserem Blog: www.zoeliakie-austausch.defindest Du immer die aktuellsten Events, Rezepte und Urlaubstipps.

5. Hier geht es zu unseren Gruppenregeln: http://www.zoeliakie-austausch.de/…/gruppenregeln-fuer-uns…/

Im Web: http://www.zoeliakie-austausch.de/…/gruppenregeln-fuer-uns…/

Bitte lesen und bestätigen.

6. Unsere Infos gibt es auch als "Hörbuch". Der Link zu unserem Einsteiger Podcast (natürlich kostenlos):http://www.zoeliakie-austausch.de/zoeliakie-austausch-podc…/

Viel Spass bei uns wünschen Jürgen und Patrizia Schmidtlein, unsere Admins Hannah Dreßen, Rebekka Fortuna, Andrea Lindow, Heiko Bernhoerster, Melanie Huber und Christian Eberle, sowie tausende liebe Mitzölis.