

Celiac Disease and the Use of Anecdotal Evidence to Profess Expertise

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By  
Marie Herman  
Nursing Major

The College at Brockport  
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Thesis Director: Dr. Denise A. Copelton, Associate Professor, Sociology

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### **Abstract**

Celiac disease is a complex autoimmune disease associated with adverse effects after ingesting gluten, the main storage protein of wheat, barley, and rye. Gluten triggers an autoimmune response in the small intestine, destroying the villi that absorb nutrients, causing gastrointestinal distress, malnourishment, iron deficiency anemia, and other symptoms. The only treatment is a gluten-free diet. Celiac diseases' often lengthy diagnosis process, disproportionate rate of diagnosis, and high prevalence in the United States makes it an excellent disease to study in an effort to gain a better understanding of people's experience of the diagnosis process. I analyzed a systematic random sample of 142 posts on pre-diagnosis and symptoms on a public celiac discussion board using QDA Miner, a free qualitative analysis program. I used the grounded theory method of open and focused coding to explore how participants request, give, and receive information on the diagnosis process. People on the forum establish lay expertise through the use of the anchor of medical jargon; profess knowledge of celiac disease tests, genetics, and symptoms; and use anecdotes alongside these anchors to support their claims. Unlike the artificial settings used in experimental research, this ethnography of an online discussion board demonstrates how people use both anecdotal and statistical evidence to profess expertise in the real world.

## Introduction

Health care professionals have been increasingly concerned with the rise of lay expertise and the use of anecdotal evidence. Many health care professionals feel that patients prioritize lay expertise, which is expertise created by nonprofessionals, making it harder to convey evidence based knowledge to their patients (van Bekkum and Hilton, 2013). In this thesis, I look to answer the question: how do participants profess lay expertise on a celiac disease discussion forum?

Celiac disease is a complex autoimmune disease associated with adverse effects after ingesting gluten, the main storage protein of wheat, barley, and rye, products found commonly in the American diet (Fassano and Catassi, 2012). Celiac affects an estimated 0.71% of the United States population (Rubio-Tapia, Ludvigsson, Brantner, Murray, and Everhart, 2012). When gluten is consumed, it triggers an autoimmune response in the small intestine, destroying the villi that absorb nutrients. This can cause gastrointestinal distress, malnourishment, and iron deficiency anemia, and is associated with high risk of gastrointestinal cancer. Left untreated, celiac disease can lead to death (Fassano and Catassi, 2012). The only treatment is a lifelong gluten free diet, meaning the person can no longer eat foods that contain gluten, including most breads, crackers, cakes, and other foods. It can be overwhelming for some and although a gluten free diet alleviates symptoms, its restrictiveness can lead to a perceived lower quality of life (Lee and Newman, 2003). Although a diagnosis asserted by a lay person can bring some relief (Copelton and Valle, 2009), research is unclear on the power of anecdotal evidence over evidence-based knowledge.

## **Background**

### **Lay Expertise**

People go online both to seek out and profess medical expertise, resulting in lay expertise. Lay expertise is defined as the capabilities and knowledge of a professional field that lay people may develop due to their own acquired experiences. In order to create lay expertise, people have to attach it to something that has social credibility. One way that people profess expertise is through the use of anchors. Foley and Faircloth (2003) described anchors as already respected facts of a story that serve as proof of the story's own legitimacy. For example, in their effort to legitimize midwifery, Florida midwives anchored their wholistic approach to the medical model, a model that already has social respect. In the case of the body builder's forums analyzed in Hall, Grogan, and Gough (2016), participants used pharmaceutical and biological terms as anchors to legitimize the use of synthol, a controversial supplement with questionable pharmaceutical and biological effectiveness. The use of anchors contributes to the creation of lay expertise.

When people form virtual relationships with others who have the same illness, they create connectivity. Connectivity creates a culture of tacit knowledge and lay expertise increasing challenges to scientific expertise as the use of the internet and its contribution to lay expertise increases (Barker and Galardi, 2011). People use online discussion boards to learn how to navigate the healthcare system in order to get what they want. The connectivity created on these boards fosters a heavy reliance on lay expertise. The creation of lay expertise relies on other factors as well.

### **Anecdotal Evidence / Base (Statistical) Evidence**

Lay expertise may be created through the use of anecdotes and base (also called statistical) evidence. Anecdotes consist of individual narratives and stories while base or statistical evidence relies on statistics and scientific research. While anecdotal evidence is processed in the experiential part of the brain and statistical information is analyzed in the analytical part of the brain, people use both on an everyday basis to make decisions (Gutierrez and Cohn, 2018). How much weight people grant to anecdotal evidence versus base (statistical) evidence is unclear and both types of evidence is used on celiac disease discussion boards.

Many studies examine the use of anecdotal and base (statistical) evidence and the way they impact the listener. Greene and Brinn (2003) found that compared to anecdotal evidence alone base (statistical) evidence regarding the ill-effects of tanning increased the rate of people deciding against using tanning beds. This suggests that base or statistical evidence has more impact on the listener. Allen and Preiss (1997) found that out of the 16 studies analyzed, base / statistical evidence exclusively swayed a higher percentage of people over narrative evidence alone. However, compared to statistical evidence alone, when offered both narrative and statistical evidence in a hypothetical scenario regarding bypass surgery, people were less likely to choose bypass surgery regardless of whether or not the narrative data supported bypass surgery as the more effective option. This suggests that anecdotes make risks more apparent to the listener (Ubel, Jepson, and Baron, 2001).

In their analysis of narrative evidence's impact on risk assessment of vaccines, Betsch, Ulshöfer, Renkewitz, and Betsch (2011) found that perceived risk of vaccines increased and intention to vaccinate decreased when anecdotes demonstrating the harms of vaccination were shown to the participants. Specifically, emotionally filled anecdotal evidence depicting negative

reactions to vaccines influenced participants to hold more negative views of vaccines. Gutierrez, and Cohn (2018) found that compared to base / statistical evidence alone, anecdotes about drug use paired with statistical evidence depicting the negative consequences of drug use increased the perceived risk of taking the drugs. In comparison to base / statistical evidence alone, base evidence alongside anecdotes portraying positive experiences of drug use showed no difference. Although these studies provide valuable information on how people process information, none reflect how information is accessed in the real world.

Medical information is frequently exchanged on online discussion boards. This data is easily accessible and provides the basis for this virtual ethnography.

### **Celiac Disease**

Serologic testing is often the first step in diagnosing celiac disease. The Tissue Transglutaminase Antibody test looks for antibodies in the blood made by the body's immune system against its own intestinal tract in response to the ingestion of gluten in people with celiac disease. This test has a sensitivity range of 78-100%, so it is used most often by health care providers to screen for celiac disease and determine if further testing is necessary (Rashid and Lee, 2016). The test has a lack of sensitivity in children under two years of age due to this age bracket's underdeveloped immune systems. Therefore, the more sensitive Deamidated Gliadin Peptide test is recommended addition to the Tissue Transglutaminase Antibody test in this younger population resulting in fewer false negatives (Rashid and Lee, 2016). The gold standard of diagnosis is the small intestine biopsy which tests for villi damaged by the autoimmune response to gluten.

There are several barriers to obtaining a diagnosis, including an inability to pay for testing, as well as patients and health care professionals' lack of knowledge of celiac disease

(Barbero, Donohue, and Kagnoff, 2014). A lack of a sufficient number of biopsy samples can result in a false negative. Also, false negatives are common when the patient has already stopped eating gluten, allowing the villi to heal. In the later situation, the patient would need to reintroduce gluten prior to testing, something referred to as a gluten challenge. However, many prefer not to resume eating gluten as they do not want symptoms to return (Catassi and Fasano, 2010; Copelton and Valle, 2009).

Health care providers in the United States diagnose celiac disease at a lower rate compared to those in Western Europe (Green et al, 2001). Because of this, there has been a movement by patients towards self-diagnosis of celiac disease using at home direct access tests, including stool anti-body tests, in an effort to gain social support. Due to the lack of evidence-based data to support the direct access test, many health care professionals question the test's legitimacy (Copelton and Valle, 2009). Whether through medical or self-diagnosis, one aspect remains constant with people diagnosed with celiac disease- in order to prevent symptoms, a person must adopt a gluten free diet (Bascunan, Vespa, and Araya, 2016).

The challenges faced throughout the diagnosis and dietary treatment of celiac disease are substantial. The circumstances surrounding celiac disease make it an excellent disease to study to gain a wider understanding of the patient's understanding of the diagnosis and the role that anecdotal evidence plays in the profession of expertise.

### **Methodology**

I conducted a virtual ethnography of one celiac disease discussion board. The board was chosen for its high user volume and public format. Discussion boards consist of a community of people posting questions, comments, or concerns online on a specific topic, known as a forum, which consist of threads. Threads consist of an original question or thought and the responses to

said questions or thoughts. Although discussion board participants had to sign up to contribute to the board, people do not have to register to view the content. Therefore, posters should have no expectation that their posts are private, making analysis of threads akin to observations made in a public space (Barker, 2008). I collected threads from a forum that focused on celiac disease testing and symptoms. To ensure that the discussions were complete and not ongoing, I used threads from 2015. I used systematic random sampling to select every fourth thread in the forum for a total of 142 threads.

My research methodology is qualitative in design. I used the grounded theory method of open and focused coding discussed by Charmaz (2006) with the assistance of the coding software QDA Miner. Open coding involves reading written data and assigning codes to main ideas exhibited in the data. Focused coding involves going back over the data with more specific codes to gain a deeper understanding of the data (Charmaz, 2006). I labeled one code “Facts” which included information about celiac disease, and it is with this code I noticed the use of information in posts without citing where the information came from. It is because of this that “Facts” evolved into “Proclaimed Facts.” Another code called “Self-Parallels” included all instances participants added their stories to someone else’s thread and it is with this code that I started to notice a growing trend of the use of anecdotal evidence in support of a poster’s claims. “Self-Parallels” became “Anecdotes” to cover stories that were not just about the individual but what they have seen. The code “Try GFD” included instances of posters suggesting the use of the gluten free diet, which illuminated the trend of persuading other’s in certain directions on the forum. The persuasion in “Try GFD” was clear at the end of many posts and expanded to include the function of wrapping up the persuasion of any idea, leading to the code “Conclusion”. “Self-

Parallels,” “Facts,” and “Try GFD” resulted in focused coding surrounding the exchange of information and are the primary coding categories on which I base this thesis on.

## **Results**

Discussion board participants used a common template, a general order to the paragraphs and their sentence structure, to profess lay expertise. This template consisted of reassurance, proclaimed fact(s), anecdote(s), and a conclusion. Although some posts ordered these elements differently, and some did not follow the template at all, many do. Out of the 142 threads I analyzed, 64 of them included posts that used the template at least once for a total of 156 posts that fit the exact template. This is a substantial number considering that two threads on the forum had no responses. Although these were included in the 142 thread count, because there was no interaction between posters, it was highly unlikely for the initial poster to be profess expertise. Eleven of the threads had one response to them leaving little to analyze as well. Also, three threads did not request knowledge or expertise. These three threads instead functioned more like a team bonding exercise or statement of facts. One poster asked for the foods people were most sad about giving up, resulting in responses that included foods varying from baguettes to pizza. The others were statements of having obtained a diagnosis and gratitude towards the forum. Nevertheless, the template represents the dominant format used to profess expertise on the forum.

### **Reassurance**

The first part of the four-segment template participants used was reassurance. Reassurance, as the name may suggest, involves replying to a post by reassuring the other poster in some shape or form. The replier does this in two different ways, either through agreeing with

the facts at hand or by disagreeing with a negative attribute that the original poster attached to themselves.

For example, one person posted that they were having gastrointestinal issues symptomatic of celiac disease. After experiencing celiac disease symptoms, this participant's blood tests suggested celiac disease. However, when their health care provider performed a biopsy, it came back as negative, so they have been unable to obtain a diagnosis even though they feel they have celiac disease. The original poster wonders how important it is to obtain a diagnosis. One replier ignores the question and states what they feel is the truth.

You have celiac. The small intestine, if spread out, is the size of a football field.

Of course they missed the damage, but with numbers that high on your blood work, I'm sure it is there.

Notice how this participant reassures the previous poster that they do in fact have celiac disease. The participant repeats this idea twice after explaining their rationale for why they agree with the original poster about their self-diagnosis. By agreeing with the original poster at the beginning, they catch the original poster's attention, reassuring the original poster that they are in fact listening.

Another participant had troubles in the past obtaining a diagnosis for their son and said they had posted to the discussion board before. Eventually, celiac disease was ruled out by their gastroenterologist and they made what they thought was an educational appointment with their immunologist. The participant's immunologist ended up suspecting celiac disease. Now the discussion board participant is requesting further information on how to proceed, namely, who they should trust. One response starts with the sentence "I am sorry that this is so confusing for you, but I am glad you are still fighting for a correct diagnosis!" By stating "I am sorry" the

replier is saying that they feel it should not be this hard on the original poster, but unfortunately it is, and the replier feels bad that it has to be that way. The replier then ensures the original poster that they are on their side and are “glad” that the original poster is “fighting for a correct diagnosis.” Not only does the replier position themselves on the original poster’s side, but they also position both themselves and the original poster as against the health care provider, “fighting” each other. By doing so, the replier not only empowers the original poster, but their posts serve to signify the forum members banding together against the health care system. This parallels what Barker and Galardi (2011) witnessed in the breast cancer forum where posters would stand in solidarity with one another in support of breast cancer screenings using empowering terms against the people who did not share their experience (health care providers.) The participants argued that since the health care providers did not share their experience, they should not have a say on how often is too often to screen for breast cancer.

One participant’s doctor diagnosed them with celiac disease based off of blood work and symptoms alone, without the gold standard of the biopsy. The gluten free diet worked for them, with a reduction of symptoms. However, symptoms returned. Their new gastroenterologist wanted to repeat the testing and advised the poster to do a gluten challenge. Now the poster was looking to the forum for support and advice on what they may or may not want to request of their doctor now that they have been undergoing the gluten challenge and eating more gluten than their doctor even requested. One response was not at all supportive of a gluten challenge.

Why is your doctor insisting on a gluten challenge? To me that makes no sense as you were already diagnosed and did quite well for a long time. That diagnosis should be in your medical records despite your not having the endo at that time.

The replier does not agree with the original poster being back on a gluten filled diet after already receiving the celiac disease diagnosis. Even though the original poster has made it clear that they do not play a passive role in their health and do in fact help to make health care decisions, this response still chooses to focus on the doctor and their role in the decision making. This respondent disagreed strongly with the person's doctor. By doing so, they align themselves with the original poster, reassuring them that they have good reason to question their doctor. The result is trust built between discussion board participants.

Another participant posted what can only be considered a goodbye speech. This participant talked about the long journey they have had trying to obtain a diagnosis, including the symptoms that have caused it and all the testing they have had to go through. After consulting a celiac disease specialist however, they were told they do not have celiac disease. They express guilt for having wasted a specialist's time and ambivalence about their diagnosis, stating "...i feel so embarrassed and like a hypochondriac- as if I've imagined all the side effects that I had since going back onto gluten- honestly, I felt like crawling under a rock I felt such a time waster especially as this doctor is a coeliac specialist! Oh well, I guess I need to be thankful that I am well and dont have anything serious wrong..." A participant responds to their state of conflict by saying "That really doesn't have to be it. If you aren't happy with the answers you are getting, get a different doctor." By appealing to how the original poster feels, this responder positions themselves on the poster's side.

Reassurance is used in many aspects of day to day life. Studies show that reassurance can change patient outcomes (Leibowitz, K.A., Hardebeck, E.J., Goyer, J.P. et al.; Traeger, O'Hagan, Cashin, and McAuley, 2017). It should be no surprise that people on the celiac forum use reassurance in their posts. However, at 236 times, it is surprising how often it was used and the

impact it seemed to have on its audience. By using reassurance at the beginning, responders align themselves with the original poster catching their attention and putting their best foot forward.

### **Proclaimed Fact**

The next part of the template is proclaimed fact(s). I label them as proclaimed fact(s) and not just fact(s) because although the facts at hand may be true, the author never cites outside sources or studies to verify their claims. This means that for all the reader knows, the poster is wrong. However, the author states their post with such confidence of its factuality, that readers may take the information at face value.

One parent put their son on a gluten free diet to see if gluten was what was causing his gastrointestinal distress. Unfortunately, the son slipped up and ate gluten during this gluten free trial. The parent took to the forum to ask what participants thought they should do next. The parent originally had put their son on a dairy free and gluten free diet. They had planned to do a gluten challenge later to see if symptoms returned. The question at hand is whether they should reset the test or keep going with it, ignoring the slip up, or, if they should start a gluten challenge ahead of when they wanted to since their son had already slipped up. After reassuring the parent that the slip up will not impact too much and that people should really seek long term change when removing foods from a diet, this participant then proclaims a number of facts.

Normally, a gluten challenge is the name of a period of time prior to celiac disease testing when the patient eats the equivalent of about 1-2 slices of bread for 8-12 weeks. Your son has only been gluten-free for 18 days so he may not need to resume eating gluten for the 2-3 months that most people would require if they had gone gluten-free for a few months. Resume gluten consumption for a month or so and then get tested.

They then went on to list the standard tests used to diagnose celiac disease, emphasizing “Get as many tests done as possible because these tests can miss up to 1 in 4 celiacs. The more tests done, the more likely it is to be caught.” The scientific details provided in the response function as the anchor for the recommendations. The author does not cite where the information comes from. Rather, s/he states it as a matter of fact, written like a textbook without any first-person narrative and lacking any claims to personal experience. The proclaimed fact relies on tacit knowledge of the health care field, stated as something that applies universally.

In a separate example, one participant wrote about having a positive tTG test at 12.6 and a negative reticulin test. Even though one test was negative, their rheumatologist told them that they do in fact have celiac disease. The participant asks the forum if it sounds right. One participant agreed with the rheumatologist and then offered an explanation using statistics “The reticulin tests were not that reliable and missed too many celiacs. Not many labs still use them. The tTG IgA is the most common tests with a specificity to celiac disease of 95%.” The participant not only states that the reticulin test is unreliable, but by explaining just how specific the tTG tests are with an exact percentage, the author backs up their claim that the original participant has celiac disease without any citations or references. Due to the fact that the author does not cite where they got the information from, the statistic is a proclaimed fact.

In a third example, a participant asks whether having a positive TTg but a negative antireticulin means what their rheumatologist says it means- that they have celiac disease. Another participant replies to the thread, reassuring them that it is probably celiac disease and providing suggestions on how to get a proper medical diagnosis.

Are they planning on doing the endoscopic biopsy to confirm the diagnosis? If so, you'll need to be eating gluten in the 2-4 weeks prior to the procedure so you may

not want to go gluten-free yet if you are having it done. Many celiacs find it really tough to go back on gluten after starting to feel better.

There are no clear-cut science terms in this text. However, the author is giving the participant advice on how to correctly prepare for an endoscopic biopsy in order to receive a diagnosis. They list 2-4 weeks of eating gluten prior to obtaining the biopsy as if this number was a guarantee of accuracy. The information is conveyed with certainty and stated factually as if in a medical pamphlet, but with no citations to outside sources, there is no guarantee of its accuracy.

Proclaimed facts are statements made in a way as if they are facts, but because the information is not cited, it can just as easily be false, hence the proclaimed label. Base evidence and medical knowledge, even without knowing where they come from, seem more legitimate than anecdotal evidence alone. Therefore, to profess expertise, participants frequently tie their recommendation to proclaimed facts. The proclaimed facts these participants include act as the anchors to their arguments.

### **Anecdote**

I labeled the third part of the template anecdote. An anecdote consists of the poster extrapolating from their own personal experience, an anecdote, to the rest of the population. According to Gutierrez and Cohn (2018) anecdotal evidence tends to have a mixed impact on participants when it is separated from base / statistical evidence. However, in the real world, as we see in the forum, base / statistical evidence and anecdotal evidence are often presented together. This allows the reader to weigh anecdotal evidence more heavily in decision-making than they believe they are.

One participant on the board wrote about their trials dealing with gastrointestinal symptoms and going on the gluten free diet because of it. They have not been as stringent on the

diet as they should be, and symptoms returned. This participant is now looking to see how they may get a diagnosis and what people's thoughts are about their situation. One participant gives them the information they requested, and then proceeds to tell them an anecdote about their own lives.

I understand the need to have validation. I am formally diagnosed, but my husband is not. He went gluten free 14 years ago per the poor advice of my allergist and his GP. We know gluten makes him sick, but there is no way he'll do a gluten challenge. He does say that I have received more support from medical, family and friends. But even still it is hard and I get those "looks" about be[ing] gluten free.

In this reply, the author outwardly sympathizes with the original poster by agreeing with the need to obtain some form of validation. They use two anecdotes, one about themselves and one about their husband, on how an official diagnosis does or does not help. The author explains their own strife, perhaps in hopes of validating the strife of others. But what this also does is explain the diagnosis process and need for validation on an individual level, using the author and their husband as examples. It is important to note that the original poster did not request people's stories on the diagnosis process. Rather, they were looking for information on how to obtain a diagnosis after going gluten free, but the responder offers the information anyway.

Another participant ended up obtaining a diagnosis but is confused by how much information their health care provider is giving them. The participant is confused on what the health care provider deems an appropriate gluten free diet as they have never heard of the "celiac free" label their health care provider speaks of. Here is one response:

I too have never seen a "celiac free" label. There are gluten-free labels and CERTIFIED gluten-free labels. The certified ones are on foods that have been tested so you know without question they are safe. [G]luten-free labels on most things in the grocery store have not necessarily been tested but under a new law that was passed (in the US) last year, they SHOULD be gluten-free. If people have problems with a food and notify the FDA they will go in and test them. If it turns out they are NOT gluten-free, the company gets into trouble. I think most companies want to avoid that kind of trouble so generally speaking, I trust the gluten-free label.

In this reply, the author backs up their argument with their own personal experience with the celiac free label. Due to the fact that they have never seen the label, it must not exist. Then the replier describes what labels they trust, which includes the gluten-free and certified gluten free labels. In this example, the lines between anecdote and proclaimed fact are blurred, as they switch between first person and third person. This was a common pattern in the form, as in regular conversations. However, this pattern may illustrate the use of anecdotal and base/statistical evidence together to create an argument that is more persuasive than base evidence alone (Betsch, Ulshöfer, Renkewitz, and Betsch, 2011; Gutierrez, K. M., and Cohn, 2018).

In another example, one concerned parent asked:

Does this make sense to anyone? I'm going to get the actual lab report tomorrow, but until then I'm going off of what the nurse told me. Negative for everything but weak positive for the endomysial antibody. From what I'm reading, this doesn't make any sense... I have hashimoto's and my 3 year old was just diagnosed [with] Celiac, which is why I got tested.

In response, someone urges the original poster to go gluten free just to be safe. They explain that they have "...seen 2 or 3 people have a positive EMA IgA with a negative tTG IgA in the past few years on this board. It is not common, but it does happen." Not only does this participant reflect on what they have seen on the board itself, but they also use their experience on the board to extrapolate on how common a positive on one test and a negative on another test is. What makes this post important is that it reflects what many members on the forum repeatedly state, and emphasizes that what is seen on the forum is the equivalent of real world experience.

### **Conclusion**

I labeled the last part of the template conclusion. At the end of their posts, posters reiterated or summarized exactly what they had just said, almost like a conclusion. So, the sentence or sentences were more than just to make the previous poster feel supported. The last part of the post served to reiterate the poster's expertise. This conclusion was apparent in both posts that fit the template as well as those that did not.

Another poster's child was tested and ruled out for celiac disease and wants to know if they obtained all the tests they needed to rule out celiac disease. After reassuring the original poster that the tests and their results look right, in wrapping up their post, they write:

Those tests look good for your kids. Again, the EMA IgA is missing, but it tends to indicate more advanced disease, so it is not always positive in young children. Be aware that if they test negative now, you still need to retest them every two years if they continue to eat any gluten. Celiac can develop at any age so they'll need to be aware of it for their entire lives. Good luck with the doctors, and welcome to the board.

The replier agrees with the original poster that the children do not have celiac disease. However, they do not state it as an agreement with an author but rather an agreement with their argument that the tests ordered are right. These last few sentences simplify what the author of the post was discussing for the entire post and serves to reiterate or a profession of expertise.

In another example, a person wrote about their son's long history of unspecified symptoms that they believe may be linked to celiac disease. After years of trying to figure it out, they made their son an appointment with a gastroenterologist. They are now wondering what types of tests they should request on top of the list of tests they already have. In response, one person discussed the impact that celiac disease may have on kidneys, the pituitary, and the thyroid and how the original poster may discuss this with their health care provider. The participant then concludes:

Good luck with the gastro. Go in there with your lists of tests and symptoms. Bring in his abnormal test results. Hopefully he can help.... Let us know how it goes.

These sentences serve as a conclusion, or a reiteration of the participant's argument. The first of the last sentences assume that the original poster will go to the gastroenterologist as they had suggested, wishing the original poster good luck. Then the second and third sentence orders the original poster to do just as they had originally discussed. Finally, the fourth sentence assumes that the original poster will do as they requested and that the event that will stop their plans on getting a diagnosis from working is if the original poster's health care provider cannot help.

Another participant posted about their daughter's various symptoms and tests, having not obtained a diagnosis yet. They believe that their daughter has dermatitis herpetiformis, a scratchy skin condition believed to be linked to celiac disease. The participant shares their daughter's test

results and asks for suggestions regarding managing symptoms and why health care professionals will not diagnose their daughter. The replier explains that the tests are within normal range and how immunoglobins work for celiac disease diagnosis tests. However, the tests the original poster posted are not what the replier deems as celiac disease diagnosis tests. Since the results do not correctly diagnose celiac disease when a patient has dermatitis herpetiformis, they feel that the original poster's daughter may not get a diagnosis that way. This poster wraps up their thoughts with a conclusion:

There are no celiac tests in all of those results. From what I know, those with dh do not test that accurately for celiac disease compared to others.

Best wishes to your girl... That looks very very painful.

These last few sentences are very author-centric, involving what they feel and know. The poster reiterates their thoughts, summarizing their points, but it is only until the last two sentences that they bring up the original poster's daughter, the subject of the post. It is because of this reiteration of thoughts, that their sentences serve as a conclusion.

Many posters used the conclusion at the ends of their posts, including in posts that did not fit the template. Although many people seemed to use the conclusion to affirm the former person's thoughts, based on what I have seen, the main point of the last sentence(s) was to reiterate that person's beliefs. By reiterating their own beliefs, posters are able to further legitimize their argument, aiding in the profession of expertise.

## Template

Previously, I had demonstrated each aspect of the template using separate quotes that best exemplified each part of the template in the most clear-cut way. However, it may help to see an entire post that shows the template from start to finish.

The below post was in response to a mother who was questioning her provider's interpretation of her child's blood test result, and whether they are behaving 'neurotically' by questioning that interpretation.

I don't think that you are a neurotic mom. He has symptoms and a positive test. To [m]e, it makes sense that you would look into it more. The tTG IgG is very specific to celiac disease, 95% of positives are caused by celiac disease, so it is likely that he has celiac disease. Some people, young children and those with early celiac disease, will end up with false negatives (as high as 25%) so that could account for the other negatives. I would say, based on what I have seen around here, that around half of all cel[i]acs end up with a negative blood test, whether it is blood or endoscopic biopsy. It really can confuse things...and doctors. Lol False positive tTG IgG tests can happen but they are not common. It is much much more likely to get a false negative with this test. False positives in the tTG IgA version are caused by thyroiditis, diabetes, crohn's, colitis, chronic liver disease or a serious infection. If they don't think he has celiac disease, they might want to look into these problems... But if it looks like a duck, and quacks like a duck, it[\*]s probably a duck.

The poster first reassures the concerned mother that she is not neurotic and that they understand where the mother is coming from. This functions to gain the reader's trust. Then the poster uses

many proclaimed facts, incorporating statistics without any sourcing. These proclaimed facts act as anchors giving the entire post greater legitimacy. Then the poster adds an anecdote which is his/her estimation of the population of negative results based on what they read on the board. The point of the conclusion is not so much to reassure the original poster, but to reiterate their own claims.

Many posters agree with other posts on the forum, reflecting the nature of connectivity on the forum. However, a few did not, and I thought it would be worth noting a particular exception, as, not only does it vehemently disagree with the previous poster, but the author does so through the use of the same template I have been citing. Of course, instead of affirming the poster they are responding to, they are affirming another poster's viewpoints that were more in line with the rules created through connectivity on the forum.

The thread starts off with a post asking what others may feel may help people during the occurrence, diagnosis, and treatment of celiac disease. One participant responds with a desire to have more support since every social activity they have seen involves glutenous food. This participant references work potlucks where they are not able to enjoy socializing because gluten in the air makes them sick. Another participant chimes in stating that the inhalation of gluten cannot make one sick, only the consumption of gluten. The participant that wanted to attend more social events responds back with irritation that the other participant cannot simply tell them what they feel since they have had celiac for a long time. Finally, another person agrees with the individual who corrected the one requesting more social support.

[username].....what [username] stated is 100% correct. You cannot initiate the autoimmune response by smelling food, it has to enter the GI tract and that means it starts at your mouth. But let me say something else here before you

become offended over something that should not offend you. I know exactly how you feel because I have the same "reaction" to strong gluten smells, most notably pizza... I have learned over the almost 11 years I have been gluten-free that those are psychosomatic reactions.... But in no way is it a true Celiac reaction because if it were, none of us would ever completely heal. We would have to shut ourselves away from the smells of life out there. This is one of those things that our subconscious is in control of, at least I think it is....

Do not shut yourself away from life because you have Celiac. You sound angry about it, but remember, this does not define us. It may help to talk to someone about your fears and aggravations about having Celiac. I know you won't like me saying that but just give it some thought so you can rejoin the human race and live like everyone else does and enjoy yourself in a social setting. It matters to your long term well being. Best wishes to you!

In this instance, the response matches the template, but instead of agreeing with the previous poster, they are disagreeing with them. The poster reassures the original poster that they are wrong. Then the poster adds a proclaimed fact about the autoimmune response. They then go into their own struggles with gluten, and finally wraps it up with urging them to listen to them and attend social events that may contain gluten. It is important to note that even when disagreeing with the poster at hand, they still equate their experiences to the poster's experience. Instead of alienating them, they are sympathizing with them. The anecdote in this post actually plays a different role than most anecdotes in the template. Whereas they usually prove the facts at hand, this anecdote is meant to encourage the previous poster to take their statement well and not aggressively. Their anecdote becomes a basis for shared experience and a way for the other

participant to possibly listen to them, to persuade them of the facts (albeit proclaimed facts as the author never cites their source,) at hand.

### **Proclaimed Fact, Or Is It**

I originally expected that posters would use hyperlinks to anchor their knowledge. Instead, I saw more posts that did not link or cite anything but professed medical knowledge / statistics / tests as the anchor without citations. Only a total of 130 posts included a hyperlink outside of the discussion board as an anchor. Many of these posts still did not rely solely on the hyperlink as their anchor because they also included proclaimed fact(s) not cited in the hyperlink. Posts that did not include other proclaimed facts and relied just on the hyperlink as their anchor actually used it less to profess expertise and more as a diversion of responsibility. These participants would post the link but insist that others speak to their health care provider, the true professional, or even, they would post the link and instruct the original participant to check it out for more information with no further explanation.

One example of this occurred in response to a participant asking if their situation makes sense to any of the forum members. This poster tested negative for many celiac tests but had one weak positive result. They also have Hashimoto's disease and their son has celiac. In response, one participant included a hyperlink to explain why they believe a gluten free diet may be a good option.

I think I would go gluten-free too, just to be safe. Autoantibodies tend to linger in the blood stream anyways, so going gluten-free sooner rather than later is a good idea. I've seen 2 or 3 people have a positive EMA IgA with a negative tTG IgA in the past few years on this board. It is not common, but it does happen. That test is VERY specific for celiac disease, 98-100% specific, so if you have a positive, you

most likely have celiac disease. A 0-2% chance that positive was caused by something else... That's pretty slim. See page 12 of this report for the details: [http://www.worldgastroenterology.org/assets/export/userfiles/2012\\_Celiac%20Disease\\_long\\_FINAL.pdf](http://www.worldgastroenterology.org/assets/export/userfiles/2012_Celiac%20Disease_long_FINAL.pdf) Plus you have a family history of celiac disease, and Hashi's which is strongly linked to celiac disease (I have it myself), and some symptoms too?. I'd say that is celiac disease. I don't believe in coincidences in medicine anymore.... Coincidence is doctor-ese for "I'm not 100% sure what is going on" or "I wasn't trained in this". Best wishes and welcome to the board

The citation acts as the anchor in this scenario because the participant asks the original poster to see the details on the science behind the disease in the link. Ironically though, it is worth mentioning that, at least on the page number of the pdf the poster recommended, the source does not actually support their claim. It does not even reference the EMA igA and tTG igA tests or the specificities that they mention and is in fact focusing on the HLA-DQ2 and HLA-DQ8 genes!

The HLA DQ2 and HLA DQ8 genes are the genes associated with celiac disease. The proportion of the celiac disease population with both or one of the genes ranges. Avesh, Zaqout, and Yassin (2017) found either of the genes in 90.8% of the celiacs they studied, while 93.2% was the number cited by Castro-Antunes, Crovella, Brandão, Guimaraes, Motta, and Silva (2011). Cecilio and Bonatto (2015) estimates 98.4% but Kårhus, Thuesen, Skaaby, Rumessen and Linneberg (2018) estimates 100%. The numbers vary in the research, but the most commonly cited figure on the discussion board was 97%. The fact that the figure used is almost always 97% demonstrates that once something is stated on the board enough times, it becomes the culture of the board to repeat it. However, I was unable to find the 97% figure in any published studies. This highlights the connectivity, or the exchange in information online

resulting in an agreed upon story and facts, mentioned by Barker and Galardi (2011). This also shows that proclaimed facts are a sort of anecdotal evidence in and of themselves, particularly if they are not entirely accurate.

The complete blood panel listed below was referenced enough times to make it noteworthy:

- Tissue Transglutaminase (tTG) IgA and (tTG) IgG
  - Deamidated Gliadin Peptide (DGP) IgA and (DGP) IgG
  - EMA IgA
  - total serum IgA and IgG (control test)
  - AGA IGA and AGA IgG - older and less reliable tests largely replaced by the DGP tests
  - endoscopic biopsy - make sure at least 6 samples are taken
- Keep consuming gluten until all testing is complete.

It is noteworthy for a few reasons. Out of the threads that I sampled, it only appeared about half way through the year and started off as a post from one of the active moderators. Eventually though, it was either paraphrased, quoted and cited back to the original author, or completely copied and pasted without a reference altogether. This may have been the start of connectivity, or the start of the repetition that led to a proclaimed fact, on the forum. Another aspect that makes this unique is the occasional citing back to another user, which can be the poster ensuring credit is given to the other user or they can be using the agreement of the other user as a sort of reputable source to be taken as an expert even though it is still lay expertise. This is similar to what Hall, Grogan, and Gough (2016) noticed about participants positioning themselves as experts in order to provide advice.

It seems clear now that the point of the last few sentences of many of these posts was to reiterate what they formerly said. It is especially clear learning that many of these posts contained arguments that had to not only be back up or supported by something but agreed with in order to obtain their purpose- persuasion. By ending posts with conclusions, the author is better able to convey their argument, which is why many posts ended with conclusions.

### **Discussion / Conclusion**

Discussions boards act as sources of medical information alongside the information health care professionals may give. People who use discussion boards may be more likely to raise concerns with their health care providers because of the information provided on the forums (Copelton and Valle, 2009). There is an increasing concern amongst health care professionals that patients are relying heavily on lay expertise and anecdotal evidence resulting in patients making illogical decisions about their health care (van Bekkum and Hilton, 2013). Due to the increasing role of discussion boards, it is important to understand how people use them (Barker and Galardi, 2011; Barker, 2008; Copelton and Valle, 2009).

A parallel can be drawn between how companies gain consumer trust online in order to sell their products and how participants on the forum gain reader's trust online in order to get their audience to listen to them. Urban, Amyx, and Lorenzon (2009) found that companies gained client's trust through flattery and transparency. The companies flattered their customer by claiming to understand what the customers may be going through and emphasizing how their product may help their customers help themselves. They conveyed transparency by showing honest rates of their competitors, illustrating benevolence. This flattery or apparent benevolence is reflected in the first part of the template labeled as reassurance. That is not to say that people consciously use flattery in their structures. Rather, those that start with flattery may receive more

responses to their posts and so maybe more likely to use flattery or reassurance in future posts. Reassurance often reflected the sort of illness solidarity that Barker (2008) noticed in her analysis of fibromyalgia support groups, using terms like “fighting for a correct diagnosis” to convey the sense of empowerment. By empowering the original poster, there is an increased sense of community, and so there is an increased reason to listen.

After gaining trust, many participants use the anchor of proclaimed facts. Understanding participant’s use of anchors is important for understanding why people may prioritize lay expertise over the expertise of medical professionals. Rather than just using an anecdote, posts more often included proclaimed facts, which anchor their knowledge to medicine. This appears to make the story more believable to the audience, giving credibility to the person professing lay expertise. Many of these proclaimed facts were congruent throughout the forum, exhibiting an element of connectivity.

Anecdotes are more complicated on the forum than health care providers in van Bekkum and Hilton (2013) perceived. Whereas health care professionals may see the increased use of lay expertise and anecdotes as an appeal to the illogical side of their patients, their use is a lot more calibrated as demonstrated in the template. Anecdotes were used in conjunction with proclaimed facts to make a point. Although anecdotes were used, there were many instances where they were not the center of the argument and rather were snuck in at the end. This is not to say that anecdotes had no impact on the listener. As Gutierrez and Cohn (2018) point out, anecdotes persuade the listeners when given in conjunction with statistical evidence. People on the forum appear not to blindly follow anecdotes. Rather, they follow what they perceive to be cold hard facts presented by other posters. The conclusions the posters used acted as the sort of legitimization, an act of professionalism, the same occurrence that Hall, Grogan, and Gough

(2016) saw on their analysis of a body builder's forum on synthol use with their own personal experiences. These participants do not appear to be taking anecdotes at face value, but it is rather the natural way that anecdotes are shown in the forum that may alter their reactions to the proclaimed facts at hand.

We need to keep in mind why people seek lay expertise to begin with. Symptoms of celiac disease can be very stigmatizing (Copelton and Valle, 2009), resulting in people with these symptoms to seek medical help. An estimated 0.71% of the United States' population has celiac disease (Rubio-Tapia, Ludvigsson, Brantner, Murray, and Everhart, 2012) and yet the barriers to obtaining a diagnosis, including health care professional's lack of knowledge of the disease, has led to many not obtaining the diagnosis they should have (Barbero, Donohue, and Kagnof, 2014). This has left people with the desire to find answers, which leads them to discussion boards, where they finally obtain knowledge, in the form of proclaimed facts, verified by anecdotes lived by people who have been in their shoes. Having symptoms and no diagnosis leaves people feeling vulnerable. People go to this discussion board seeking answers, and anchors in the form of proclaimed facts legitimize claims and conclusions others make so that people may believe them.

In order to profess lay expertise, people attach it to something with social credibility- an anchor. People on the forum establish lay expertise through the use of the anchor of medical jargon, specifically professed celiac disease tests, genetics, and symptoms, but they also use anecdotes alongside these anchors to support their claims. This research can help medical professionals understand how lay expertise is formulated in the real world. Unlike the artificial settings used in more experimental research, this ethnography of an online discussion board demonstrates how people use both anecdotal and statistical evidence to profess expertise in the

real world. This may have implications for other medical conditions beyond celiac disease such as the decision to vaccinate. I speculate that this template may be present on other websites not concerning celiac disease, which may account for why people choose to listen to lay expertise in the face of conflicting medical evidence. Should this 'template' be apparent elsewhere, a new tactic may be necessary in order to potentially persuade people to prioritize medical evidence.

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