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## ILLNESS AND THE INTERNET

### From Private to Public Experience

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Illness is a ubiquitous experience in all societies. Different cultures have different ways of responding to illness. Historically in Western cultures, illness is typically handled by self, kin, healers, or other specialized individuals. While the existence of illness may become a societal concern (e.g. various plagues, public health), the sufferers' experience and management of illness, while possibly culturally scripted, remain largely a private experience, until recently.

Sociologists have been studying the subjective experience of illness for nearly 50 years (Conrad and Stults, 2010). Until roughly the turn of this century, there were two consistent findings: (1) there were no illness subcultures, and (2) illness was a profoundly privatizing experience (with a few notable exceptions like the HIV/AIDS or breast cancer activist

and support groups). As the sociological theorist Talcott Parsons observed, "illness usually prevents the individual from attaching himself to a solitary subculture of similarly oriented deviants" (Parsons and Fox, 1952: 137). French sociologist Claudine Herzlich (2004) notes, "It is difficult to discern whether health and illness belong more in the private or public domain." The few studies available suggest that, even in institutions, illness experience remained individual and private, and even more so in the community (Conrad and Stults, 2010). As just one example, several decades ago, Schneider and Conrad (1983) interviewed 80 people with epilepsy and found that only 5 of the respondents had ever talked to anyone else who shared the same illness. For the overwhelming majority of people with chronic conditions, illness remained a private

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experience and shared only with family, medical personnel, and perhaps a few close friends. We are quite certain this would not be the case today. It would be an exaggeration to say that the Internet has changed everything, but it seems clear the Internet has revolutionized the interactive experience of illness, transforming illness experience for many people from a private to public experience. In this article, we will examine the role of the Internet in the facilitation of illness from a private to a public experience and the social consequences of the Internet in illness experience.<sup>1</sup>

The Internet, as we know it, with a browser for general use began in 1993 (e.g. Mosaic). Google, as an Internet search engine, appeared in 1998. This kind of potential access to online information and interconnectivity is the watershed event that made the Internet increasingly useful for obtaining information and connecting with others. There were about 360 million users in 2000, and by 2015, there are over 3 billion users worldwide (stastica.com). In the United States, 87 percent of US adults use the Internet, 72 percent of Internet users say they looked online for health information within the past year, 26 percent of Internet users have read or watched someone else's experience about health in the past year, and 18 percent of Internet users have gone online to find others who might have similar health concerns (Pew Internet Project, 2014). In short, there is a large and active number of people who use the Internet for health information and to interact with others about their illness or medical condition.

Based on their research, Ziebland and Wyke (2012) contend that there are seven health domains that drive the use of the Internet in peer-to-peer connections. The five major ones include finding information, feeling supported, maintaining relationships with others, affecting behavior, and experiencing health services. Not surprisingly, people with chronic illness and disability (or sometimes their caregivers) are among the largest users of health sites on the Internet.

As Ziebland and Wyke (2012) note, "the use of the Internet for peer-to-peer connection has been one of its most dramatic and transformational features" (p. 19). Whether people with illness go online

for information, support, advocacy, or comparative experiences, the Internet becomes a route to connections, often forming an illness subculture. In the first decade of online communities, there were a range of online mechanisms to make peer-to-peer connections including websites, blogs, bulletin boards, chat rooms, news groups, listservs, electronic support groups (ESGs), and forums. Some of these were asynchronous, in which individuals need not be online at the same time, while others were synchronous in which online users participated in real time.

Some of these websites required signing on to their accounts or joining, some had moderators, while many others were open to the public. While these Internet modes of connection differed in some ways, they all were available 24/7, many were anonymous or used screen names, most were globally available, and were "free" to anyone who had access to the Internet. Together, they created a vehicle that produced new connections, lay knowledge, and often vibrant online communities. It is difficult to know how many people these sites affected since only some participants actually posted material, while many more were observers, termed "lurkers," who would view the discussions, but did not post or actively participate. It is both the anonymity and lurking that make the actual participation difficult to measure. It is hard to estimate participation. The 1 percent rule states that 90 percent of online users do not actively contribute to Internet posts, while 9 percent somewhat contribute, and only 1 percent are responsible for generating new content. A recent study (Van Mierlo, 2014) found that this 1 percent rule was consistent across digital health social networks (DHSNs) as 1 percent of users actively contributed to content on these sites. This suggests that there are far more individuals silently participating in the various sites than are visible on screen. A study of 3000 respondents found that one in four Internet users living with a chronic condition reported going online to find others with similar health conditions (Fox, 2011). The utility of the Internet as a knowledge base and interactive venue for various diseases has transformed the nature of the experience of illness. Virtually any illness or

medical condition has multiple sites online, openly accessible to anyone interested. Without question, illness in the 21st century has moved from a private to a public experience.

## FROM WEB 1.0 TO WEB 2.0

In the past two decades, we have seen an enormous expansion of the Internet both in the number of users and in the amount of information and connections available. In terms of this article, one can see two kinds of Internet experiences, called in retrospect Web 1.0 and Web 2.0 (Cornode and Krishnamurthy, 2008). In Web 1.0, the vast majority of users are seeking already created content, which can be searched and retrieved from existing websites. Here, communication is largely in one direction, where information sought and retrieved has been already produced, often by professionally created websites (e.g. WebMD, the Mayo Clinic). In a sense, these websites are “passive”: they can be accessed but not modified or contributed to by users.

In what is often called Web 2.0, the emphasis is on *user-generated* content and visibility. Here is where users can be interactive and collaborative with one another. The users create much of the content. In the past decade, Web 2.0 has expanded with a range of interactive websites (blogs, ESGs) and especially what is called “social media” (e.g. Facebook, Instagram, Twitter). With social media, the participants create, share, or exchange information, experiences, and even photos and videos in user-defined virtual communities and networks. The numerous kinds of Internet-based social media are built on the capabilities of Web 2.0 technologies and have significantly expanded the ways in which people with special interests (e.g. in our case an illness or condition) can connect with one another as “friends,” network connections on Facebook, or through specifically created “Facebook pages.” Together, these groups facilitate the interaction and exchange of user-generated content, often to a specific group of friends. One major difference from previous Internet interaction modes, social media does not emphasize online “anonymity,” as did previous vehicles such as bulletin boards and

chat rooms. Yet, the Information Highway has been supplemented by the Interaction Highway.

## WEB 2.0 AND THE PROLIFERATION OF PUBLIC ILLNESS EXPERIENCES

Interaction on the Internet became the norm after 2000 or so. There were thousands of websites, representing virtually any illness, both well-known and unknown. For example, Barker (2008) examined an ESG for the contested illness, fibromyalgia. This was one of numerous sites that provided support, information, and advocacy for the treatment of fibromyalgia. The wide reach of illness on the Internet can be exemplified by two unusual and controversial conditions that have spawned interactive websites that are at the same time supportive, informative, and involved in advocacy. Conrad and Rondini (2010) described support groups that are depicted as “proana” and “transabled.” The proana websites claimed to provide support for anorexics, but in a particular way: claiming anorexia is a lifestyle and not a disease, providing advice on how to be a “better anorexic,” and advocating for the demedicalization of anorexia. The second case Conrad and Rondini examined went under a number of names, including “amputees by choice” and “transabled.” Subscribers who posted on these sites were individuals who believed that they were meant to be amputees (usually of some limb) and searched for others who shared the same orientation. They use a similar vocabulary as transgendered individuals: “I wasn’t meant to be born with my ‘left leg’ or ‘arm’.” Because the phenomenon of transabled is very rare, it seems likely that without the Internet, this phenomena as a potential diagnosis would not exist, since each individual might believe only that he or she had these unusual desires. But with the Internet, there are a number of interactive websites that allow the transabled individuals to exchange information, engender support for their condition, and advocate that their condition become medicalized as Body Image Identity Disorder (BIID) in the American Psychiatric Association’s *Diagnostic and Statistical*

*Manual* (DSM) with the hope that the medical profession will accept their disorder and thus provide the surgical amputation treatment they are seeking. (As of 2015, this condition is not a medically accepted diagnosis, nor are any surgeons willing to amputate healthy limbs.)

Most illnesses on the Internet are more common and have spawned many different websites, online support groups, and social networks. For example, if one googled “diabetes support group” in mid-2015, the results page tells us there are 13,300,000 hits. While it is likely the number is hugely exaggerated since there are probably hundreds of repeats, it gives an idea that there are at least “very many” diabetes support groups available on the Internet. To give another example, if one googled “celiac disease support group,” one would see that there were 636,000 hits. As a comparison, “anorexia support groups” yielded about 1,490,000 hits and “transabled support groups” a mere 6130 hits. Such numbers indicate both a proliferation of opportunities to connect with similarly ill others and a redundancy from poorly filtered hits on the Internet search. It is unclear what these numbers mean except as comparative availability of potential “hits” of one illness relative to another.

We will use celiac disease, an autoimmune disorder in which the ingestion of gluten can cause damage in the small intestine, as our example for social media and health. It is treated by eliminating gluten from one’s diet. Gluten-free diets and the diagnosis of celiac disease (and the more controversial claims to “gluten sensitivity”) are issues that have come to the public forefront within the last two decades. Our choice of illness here lies partly on the currency of the publicity of gluten and celiac disease, with most of the Internet and social media interactions occurring in the past decade. Our focus is primarily on Facebook because it has the most users and overall activity of all social media platforms, it provides the most communication variation of all social media platforms (e.g. visual, textual, community pages), and because many social media users now have accounts on other social media platforms, such as Twitter, Instagram, Vine, Google+, to name a few, yet still consider Facebook to be their “home-base” platform (Duggan et al., 2015). This example

will allow us to illustrate how individuals with celiac disease both create and interact using social media on the Internet.

## SOCIAL MEDIA AND ILLNESS EXPERIENCE: CELIAC DISEASE

The advent of Web 2.0 and active media sites such as Facebook, Twitter, and Instagram is one avenue for exploring the experience of illness on the Internet. In particular, Facebook serves as a site in which people can both anonymously and visibly view a variety of Facebook pages devoted to particular diseases as well as engage in private or restricted Facebook groups. The case of celiac disease is a particularly interesting example for studying illness on the Internet because the treatment is a *lifestyle* change involving the gluten-free diet, rather than a medical regimen of prescription medications.

Viewers can anonymously view Facebook pages sponsored by national celiac disease or medical organizations, such as the Celiac Disease Foundation’s Facebook page,<sup>2</sup> the National Foundation for Celiac Awareness,<sup>3</sup> Gluten Intolerance Group of North America,<sup>4</sup> and the University of Chicago Celiac Disease Center.<sup>5</sup> In addition to accessing basic information about celiac disease and recent medical updates, visitors to these public Facebook pages can view recent news articles about celiac disease, be alerted to product recalls for gluten-free products, watch videos for gluten-free recipes, and view photos of new gluten-free products and recipes. Public posts range from personal issues on how to talk to family members about screening for celiac disease to public announcements of upcoming gluten-free products by mainstream food companies. Regional support and advocacy groups for people with celiac disease have also created Facebook pages to facilitate local connectivity both online and offline through tips about new products and local gluten-free restaurants, as well as closed Facebook groups that are not accessible to the public enable individuals to connect on a more personal and private basis. Individuals

also post questions and comments on many public pages, which can be viewed to outside anonymous visitors from all over the United States and globally, and other online users post responses to these questions. For example, on the National Foundation for Celiac Awareness public Facebook page under a post to a video on the diagnostic delay of women with celiac disease, one woman comments on her own experience of diagnosis:

Years and years and years! That's how long! And then, after my primary doctor got a positive on the blood test, the gastro doc didn't want to take the time for the intestinal biopsy during my colonoscopy, telling me, "you're not celiac, you're only sensitive. You're numbers aren't high enough to actually be celiac," which was news to me because my primary had actually diagnosed me as celiac. So, I tell my primary doc and she tells my gastro doc to DO THE BIOPSY. After years of suffering, guess what! The biopsy was positive! Always be your own advocate. Be your best supporter and never take no for an answer but more importantly, don't ever be discredited or talked down to by a doctor.

Another online user agrees and comments,

My GI doctor was the same way! Argued with me about performing the endoscopy . . . When he came into the recovery room (while I was still asleep but could hear everything he was saying) and said that everything was flattened and I needed to start a GF diet immediately. . . . All I wanted was to sit up and scream I told you so. Lol.

These posts are not anonymous and can be easily accessed by viewing the group's Facebook page, yet online users post personal information related to their diagnosis, family history, and symptoms on these Facebook pages, demonstrating a type of support community for individuals with celiac disease facilitated by social media. These open-access

Facebook pages exemplify the transformation of the experience of celiac disease from a private illness involving a change in diet to a public experience to which a community of online users contribute and provide suggestions and recommendations on the latest updates on the gluten-free diet. Unlike Web 1.0 and online support groups, the social media connectivity in these examples of celiac disease on Facebook represents the advance of Web 2.0 as they demonstrate the interactive and public nature of social media. They are indeed virtual communities creating an online subculture of celiac sufferers. Online posts about celiac disease also blur the boundary between medical treatment and food, as the medical regimen for celiac disease is a dietary change, and serve as an example of the transformation of the experience of illness from a private to public experience that is reinforced by an active community of online users.

## IMPLICATIONS AND CONSEQUENCES OF ILLNESS AS A PUBLIC EXPERIENCE

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In considering the implications of the Internet in the experience of illness, Conrad and Stults (2010) note that "the Internet has changed the experience of illness" (p. 180), particularly through illness subcultures and public notions around illness. The Internet has served as a catalyst in transforming the experience of illness from a private experience to a public one, particularly through its variety of its characteristics: (1) in serving as an information source for patients, (2) in becoming a repository of experiential knowledge, (3) in facilitating communication and support among individuals affected by a particular condition, (4) in shaping social movements (e.g. advocacy) around illnesses and collective illness identity, and (5) in playing a role in the changing nature of the doctor-patient relationship. We will comment briefly on all five aspects of social media and its impact on illness experience:

1. The Internet serves as a source of information for patients as well as for those who provide care to family members or others with an illness. Individuals can seek information online about their own condition and the recommended treatment rather than rely solely on the physician or standard medical sources as a resource of information about one's illness. This characteristic of the Internet is particularly notable for acute illnesses in which individuals may "self-diagnose" based upon symptoms described on the Internet. In addition, many aspects of Web 2.0 are interactive in that they bridge geographical spaces and time and allow illness peers to engage in online health communities (OHCs) and information seeking from their computers (or smart phones) 24/7. However, the notion of risk is an important consequence of seeking information related to health on the Internet and engaging in these OHCs, as patients may receive misinformation from other online users. Healthcare providers do not monitor online health forums and communities, and online users can post their own opinions and experiences around their condition and medical treatments they utilized, which is available to be read by all those who access the site. Advertisements to patients about specific medical treatments also appear online and may shape patients' ideas about their own health condition.
2. The Internet allows individuals to easily seek experiential knowledge. The Internet provides a different type of knowledge and empowerment to online users that they would otherwise not receive from a physician or other medical sources. For example, online users share knowledge around particular physicians to consult, preferences for medications, and issues around one's lifestyle that they can receive online without a visit to a clinician. In addition, non-ill others, including caretakers, can learn about the illness experience from these sites. Goffman (1963) might have called this the knowledge of the "wise," individuals who understand insider meanings of living with the illness. This availability of experiential knowledge represents more of the "soft" subjective side of an illness rather than the clinical or biomedical information one may receive in a clinic visit. In a fashion, this is like joining an Internet club where individuals with an illness can interact with similar others.
3. The Internet also facilitates communication among other patients and families, particularly caregivers, dealing with illness. This function of the Internet resonates more clearly with those with chronic rather than acute illnesses. Glenn's (2015) recent article of mothers of children with rare genetic disorders demonstrates the ways in which patients or caregivers can engage and connect with other individuals who are confronted with the same illness via the Internet, especially in cases in which the condition is rare and in which the individual has never met anyone with the illness in person. OHCs in particular serve as a source of emotional support for online patient seekers, as they allow individuals to learn about and engage in their illness experience without the potential stigma present in face-to-face interactions through the anonymity of the Internet (Broom, 2005), particularly in cases of psychiatric conditions (Berger et al., 2005). OHCs also enable patients to engage in various activities of activism around a particular cause for a disease. For example, "Glu,"<sup>6</sup> an online health community for Type 1 diabetes (T1D), allows participants to connect and emphasize the importance of research on T1D, as their mission statement reads: "Glu is an active and diverse type 1 diabetes online community designed to accelerate research and amplify the collective voice of those living with T1D."

Additionally, the weight-loss bloggers that Leggatt-Cook and Chamberlain (2012) study engaged in a more indirect method of activism through their comments on the meanings of being overweight in society and “offered critical commentary on fatness that went beyond individual struggles with weight” (p. 967). This article also points to the notion that blogs shift the private experience of weight loss to a public one, in which bloggers post their individual details, struggles, and experiences about their weight publicly.

4. The Internet has changed the notion of social movements and advocacy for various diseases and the collective identity around illness, as it facilitates the virtual connection of individuals through cyberspace. For example, the Internet has enabled connectivity and virtual interactions for parents of children with autism, aiding in the anti-vaccine movement as well as spawning the neurodiversity movement among some diagnosed with autism (Baker, 2006). Barker (2008) discusses such issues of collectivity in her piece on ESGs for patients with fibromyalgia, noting the ways in which ESGs provide the opportunity for patients to share information and become “experts” and advocates for their contested illness. Social movements surrounding certain diseases are possible with the Internet, as such a virtual place allows patients to collectively mobilize in cyberspace.
5. There is also a change in the doctor–patient relationship in which there is a resistance to the traditional hierarchy, as the patient becomes active in his or her disease management and lifestyle. Hardey’s (1999) early notion when the Internet became more publicly available at the end of the 20th century that the Internet blurs the personal and professional aspects of illness remains true today, as patients are increasingly becoming active consumers of their own medical care

and knowledge around health. Conrad and Stults (2010) suggest that the Internet empowers patients and oftentimes “challenges physicians’ expertise . . . which probably does erode physician authority to some degree, but to what extent and with what consequences are not yet understood” (p. 187).

Because the Internet is used among patients to seek information and learn about one’s condition, it is important to recognize that there is no one term to describe the site of which online users gather to exchange information and share experiences. These terms are also followed by a certain acronym to shorten the phrase to describe these communities. Barker (2008) uses the term “electronic support groups,” while others use the term “digital health social networks” (Van Mierlo, 2014) or “online health communities” (Glenn, 2015). The language of an OHC is a more neutral term to describe a location for the exchange of knowledge and information than solely a site for reasons of support. Similarly, it is important to consider the language we use to refer to these individuals who access the Internet for information and support around disease and illness. These individuals can be termed in different ways, including “patients,” “visitors,” “online users,” and “online surfers,” depending on their use of the Internet as a tool in illness experience. For example, the fact that the term to describe these individuals is unclear indicates that there are new ways of thinking about the experience of illness with advances in technology in our society and the ability to engage actively in one’s own care.

## CONCLUDING REMARKS

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As this article has argued, the availability and use of Internet have transformed the experience of illness from a fundamentally private experience to an increasingly public one. This is a major transformation of the illness experience, one from which we believe there is no return. We expect that while there will of course always be private aspects of illness, the

Internet-facilitated public faces of illness will remain and probably grow. There are just too many benefits for ill or disabled people for the interactive sites to fade away. These sites are convenient, accessible from the comforts of home, via computer, tablet, and smart phone. Not only can these interactive sites now always be with us, they are 24/7 and globally accessible by our ever-present mobile phone. It is likely that as new dimensions of the Internet are created, experiential illness-oriented websites will adapt to new technologies and find ways to maintain or even expand their interactive capabilities. In this sense, there was a smooth transition from the early interactive Web 2.0 websites to the current social media connections (e.g. Facebook). Future technological advances in the Internet through new media avenues, mobile apps, or innovations that we cannot yet even imagine may change the shape of the interactive experience, but the existence of the public face of illness will adapt and remain vibrant.

There are a few characteristics of the Internet experience of illness that bear watching to see how they develop in future years. The potential of anonymity (e.g. screen names, lurking) has always been part of the attraction of the Internet and is already somewhat challenged by social media, where one of the main characteristics is individual identity (e.g. Facebook pages). Will social media or some future form of connectivity erode the anonymity that remains an attractive feature of the illness interaction sites? Related to this will many sites remain “open access” so that any interested party can join and participate? Will the Internet remain essentially “cost free” and globally available? The interactive illness websites have adapted as necessary for the past two decades, and one can only imagine that the demand is sufficient for continuing types of adaptation. The public face of illness, while recent in creation, is likely to remain a significant characteristic of illness well into the future.

## Notes

1. While there is a multitude of Internet technologies that play a role in illness experience including websites, listservs, online chat rooms, social media sites, and mobile apps, we include all of these as Internet facilitators for the public experience of illness. For social media, we focus on Facebook, the largest and most popular Internet site.
2. <https://www.facebook.com/CeliacDiseaseFoundation>
3. <https://www.facebook.com/NFCeliacAwareness>
4. <https://www.facebook.com/GlutenIntoleranceGroup>
5. <https://www.facebook.com/CureCeliac>
6. [https://myglu.org/?gclid=COf\\_k7S3psYCFREoaQodILcA0Q](https://myglu.org/?gclid=COf_k7S3psYCFREoaQodILcA0Q)

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