Redistribution of Medical Responsibility in the Network of the Hyper-connected Self

Anna Schneider-Kamp, Dorthe Brogård Kristensen

anna@sam.sdu.dk, +45 6550 4385, dbk@sam.sdu.dk, +45 6550 3884
Department of Marketing and Management, University of Southern Denmark

Abstract  The penetrating societal impact of information and communication technologies discussed in the Onlife Manifesto poses challenges and simultaneously opens new avenues in health care. In this chapter we investigate how phenomena such as hyper-accessibility and hyper-connectivity enable patients to establish a counter-expertise to traditional medical authority and to build up their own health knowledge, giving rise to new standards for diagnosis, normality, and pathology. The investigation is rooted in a qualitative study of online health communities and consumption of health-related online information in Denmark.

Keywords  Online communities, Health care, E-scape medicine, Empowerment

Introduction

The impact of ubiquitous information and communication technologies (ICTs) on the human condition has inspired researchers from a multitude of fields to found the Onlife Initiative and discuss the ensuing transformations and their impact in the Onlife Manifesto (The Onlife Initiative, 2015) consisting of four sets of paragraphs (§1.1–4.7). The distinctions “between reality and virtuality” and “between human, machine and nature” are becoming more and more blurred, fundamentally changing our self-perception and the scope and frequency of our “hyper-connected” social interactions. The “hyper-accessibility” (Ganascia, 2015) to an ever-growing body of information and the increasing inter-connectivity of things and complexity of relations profoundly impact our “conception of” and “interaction with reality” (The Onlife Initiative, 2015), challenging and even “shattering” (Ganascia, 2015) institutions of authority in the process.

This penetration of ICTs into every aspect of human existence has during the last two decades had a far-reaching impact on health care. It has challenged established institutions of medical authority, which are still largely based on the assumptions (§1.1) and structures (§1.4) of modernity. Simultaneously, it has stimulated a (re)distribution of medical responsibility (§1.3, §2.1, §3.4) and decision-making power (§2.3) in health care, broadening the horizons of individual non-institutionalized health care.

In an attempt to embrace the possibilities and challenges brought forth by hyper-accessibility and hyper-connectivity, public health systems in Northern European countries have started to provide citizens with health information as an integral part of patient education and patient empowerment strategies. Examples for this trend include the UK’s expert patient programme (Department of Health, 2001) or the Danish maternity care programme (Winthereik & Langstrup, 2010). This more traditional body of knowledge is supplemented by a much larger body of user-generated content, e.g. in the form of online health communities – see (Ferguson, 1997) for a (now) historical perspective of this (then new) development and (Johnson & Ambrose, 2006) for a systematic inquiry in the challenges and benefits of online communities.

Consequently, the monopoly on health information, held formerly by medical schools, libraries, and health professionals, has been broken. Health information of all kinds of depths and qualities is today freely, publicly, and instantly accessible through the internet. This phenomenon has been dubbed “e-scape medicine” (Nettleton & Burrows, 2003) in the medical sociological literature. Following Ganascia (2015), it can be seen as an instance of hyper-accessibility catalysing a devaluation of established authority, or as he calls it a “shattering of institutions”.
Historically, the emergence of a scientifically critical approach to medicine and its role in society at the end of the 19th century has resulted in a “vigorous debate about the boundaries of medical responsibility, one that rages to the present day and will no doubt always rage” (Nuland, 2008). Initially, the discussion grew from the observation of a correlation between diseases and social conditions, extending health professionals’ responsibility into matters of public health, personal hygiene, and even social inequality. The following century saw these boundaries extended by growth of medical evidence and diagnostic abilities, based on advances in medical research and medical technology. The responsibility of health professionals now began to extend into the patients’ personal spheres, e.g. regarding matters of lifestyle or healthy eating.

The consequent explosive growth and professionalization of the medical sector have attracted a lot of critical attention, not least since (Illich, 1974, 1976) thoughts about the limits of medicine and the power of the medical profession. Illich feared an unstoppable expansion of the medical sector, a concern recently taken up regarding the efficacy of further increasing the medical sector (Moynihan & Smith, 2002). Ganascia (2015) reflects on these thoughts, pointing out how the inability of the “medical body” to take “into account the real needs of patients” has fuelled the establishment of patient associations since the 1970s. Originally, these associations were created to supplement biomedical health care by establishing networks among patients with similar experiences and needs.

Forty years later, Ganascia (2015) finds that the tens of thousands of patient associations have become organizations of “power and recognition”, able to “impose public control over the organization of medicine”. But he also points out how their professionalization has shifted their attention away from representing “the interests of patients” to representing “their own interests”. It is on this fertile ground that we have seen the potential of hyper-connectivity to match individuals with similar needs, challenges, and interests materialized in the form of online health communities.

This chapter explores the challenges, implications, and polarizations regarding the use and production of online health information. We join the Online manifesto’s discussion on empowerment through ICTs and the ensuing distributed responsibility in our networked society.

Our context and point of departure is the health management of hyper-connected Danish citizens, who, enabled by hyper-accessibility, possess a wide variety of choices when faced with symptoms of sickness. Our exploration is grounded in a qualitative study on a range of health-related topics such as patient empowerment, self-diagnosis, and food intolerances, in a symbiosis of ethnographic and netnographic (Kozinets, 2009, 2015) methods. We spent extended time with our informants, building up relationships of trust, visiting their homes, observing their practices dealing with online health information in times of sickness, and performing long interviews (McCacken, 1988). We have joined an online health community, spending extensive amounts of time observing interactions between members, following discussions on a broad variety of topics, and in some cases interacting actively with other members.

From the many parts encountered that belong to the overall puzzle of health management in our hyper-connected world, we selected a triptych of three stories that illustrate different aspects regarding the use and production of health information online.

The first story is a nearly classic example of how hyper-accessibility to officially-sanctioned health information enables individuals to slip into the role of health professionals, but with an unexpected twist to its plot. Two manuals, one for patients and one for doctors, frame this story.

The second story expands the picture to the full breadth of e-scape medicine, leaving the safe but boring harbour and opening new horizons of self-diagnosis. It has its origins in a longitudinal study of the phenomenon of patient empowerment.

Finally, the third story takes us down the rabbit hole of online health communities, where the hyper-connected individuals become a part of the health knowledge production process. This story takes place in the context of an online community for histamine intolerance (often abbreviated as HIT).

What connects these three stories is that they exemplify how hyper-accessibility and hyper-connectivity enable patients to establish a counter-expertise to traditional medical authority and to build up their own health knowledge, giving rise to new standards for diagnosis, normality, and pathology.
Trust and empowerment in the epoch of e-scaped medicine

This chapter explores the influence of hyper-accessibility and hyper-connectivity on individuals’ interactions with health professionals as well as on new behaviours in day-to-day health management. Consequently, our analysis is based on sociological theories regarding patterns of trust as well as (patient) empowerment. These theories had to be updated to the realities of the epoch of e-scaped medicine.

In general, trust is essential for individuals to successfully navigate in our “risk society” (Beck, n.d.), where individuals base their behaviour on avoiding real and imaginary risks. In the case of health, risk avoidance and trust form the very fabric of individuals’ health management. Holmström (2007) observed that “risk cannot be transformed into security, but is a question of attribution of trust”, with the whole social order being “based on structures of expectations”. This is where trust assumes an important role in mediating social relations (Luhmann, 1989). Consequently, independently of the nature of the trusted entity, individuals need less trust when they are more confident with the situations, and more trust when situations are unfamiliar, unpredictable, and deviant.

Luhmann (1989) describes trust as a mechanism for reducing the complexity of the society on the interpersonal and system levels. According to his theory, trust can be established between two persons, unfamiliar with each other, but acting on behalf of a trusted system. This mechanism can be seen at play in today’s complex health market with its many public and private stakeholders, e.g. when patients place trust into a physician based solely on the fact that he is employed, and therefore accredited, by a public hospital. This accreditation promises power of knowledge based on his education and puts him into a position of natural authority. While defined originally in the context of trusting persons, the same process can be assumed to be applicable to the context of trusting information.

But trust is not a one-dimensional variable: individuals exhibit differing levels of trust in different entities simultaneously. Bauman (2001) presents a model of “triple trust”: trust in “oneself”, including one’s closest family members; trust in “others”, e.g. health professionals or other patients; and trust in “jointly built institutions”, e.g. in hospitals or medical associations.

In this chapter, we extend this coarse model by trust in one’s “neo-tribe” (Maffesoli, 1996) to be able to differentiate whether persons are perceived as strangers (“others”), as close acquaintances (“neo-tribe”) or as family members (“oneself”). This extension is warranted by the “hundreds of acquaintances” (Ganascia, 2015) we find ourselves connected to in our “hyper-connected world”, e.g. through social media.

The concept of neo-tribes also has a history of being applied to the study of online health communities. We discuss our findings against the backdrop of Johnson and Ambrose’s (2006) work, where they advocate “the power and potential of online communities in health care” based on considering them as neo-tribes able to satisfy the “multifaceted patient needs” by providing “continuous affective, conative, social-environmental, or other support” beyond the “point interaction” of consulting a health professional. A similar consideration allows us to analyse and discuss how patients increasingly change establish knowledge hierarchies and become producers of health knowledge.

While Johnson and Ambrose (2006) already grasped the potential for such a bottom-up empowerment of patients, they also identified a long list of limitations, holding back the realization of this potential: “access” to computers and the internet; the lack of “ease of use” in particular by the elderly; the “fragmentation” of online communities into a collection of interest groups; challenges regarding “authentication and accessibility”, “commercialism and privacy”, “safety and security”, and “trust”; as well as the dangers of “misinformation” and of creating a “generation of hypochondriacs”. We will see that while some of these limitations have been overcome in the meantime, we will find others are timelier than ever.

From a top-down perspective, empowering patients to manage “their own health care needs” (European Commission, 2013) is widely seen as a key ingredient in the “process of modernisation” of health care (Nettleton, Burrows, & Watt, 2008) towards “self-management of health and illness” (Fox & Ward, 2006). More pragmatically, patient empowerment can be viewed as an attempt to re-assign responsibility to patients, offload health professionals (Salmon & Hall, 2003), and optimise resources (Anderson, 1996).
Patient empowerment has consequently been the subject of intensive public and academic debate. Fumagalli, Radaelli, Lettieri, Bertele, and Masella (2015) survey a total of 286 scientific articles in their recent meta-study. There are many competing definitions and models for patient empowerment (Fumagalli et al., 2015; Ouschan, Sweeney, & Johnson, 2000), most of which take a “medically-centred” (Conrad, 1985) perspective, i.e., health professionals imparting power on the patient. Ouschan et al. (2000) present such a model based on three dimensions of empowerment, i.e., “patient participation” (or “involvement”), “patient control” (or “decision making”), and “patient education” (or “use of health information”).

Johnston Roberts (1999) approaches empowerment from a rather “patient-centred” perspective, viewing patients as “empowered when they have the knowledge, skills, attitude, and self-awareness necessary to influence their own behaviour and that of others”. Schneider-Kamp and Askegaard (in press) argue that empowerment should be viewed “as emerging from a bricolage of tactical interactions with social environments” and extend Ouschan et al.’s (2000) model by including activities outside the interaction of the patient with the health professional as well as by adding a fourth dimension of “patient autonomy”. By this, instead of viewing empowerment as a process solely mediated through health professionals, they return to Dunst and Trivette’s (1996) original view of empowerment as a process influenced by the social environment.

In this chapter, we employ Schneider-Kamp and Askegaard’s (in press) extended model, which offers a micro-sociological approach for distinguishing bottom-up from top-down empowerment. This is aligned with voices from the Onlife manifesto, discussing “micro-level efforts as empowerment rooted in individual and small group interests” (Simon, 2015), where “responsibility is becoming a key challenge for” individuals “in our everyday lives”.

The following three sections present our findings in the light of the three stories we selected, with a continuum from hyper-accessibility and its influence on the trust relationships with health professionals to hyper-connectivity and the consequent emergent production of health knowledge by laypersons.

Do as doctors do

One instrument commonly employed in patient empowerment initiatives is the provision of officially-sanctioned health information (Department of Health, 2001; Winhereik & Langstrup, 2010). A concrete example we encountered in our research is the high-quality health information hyper-accessible to individuals in the form of the official Danish patient manual (DK: “Patienthåndbogen”; available from http://patienthaandbogen.dk/). This manual contains medical articles edited for a broad lay audience, detailing common symptoms and medical conditions.

In their desire to avoid risks, individuals are not limiting themselves to this obvious source of health knowledge deemed to be relevant to them, though. This can be easily illustrated by considering the official Danish doctor manual (DK: “Lægehåndbogen”; freely available to the public at http://laegehaandbogen.dk/), which targets medical doctors and contains detailed instructions for (differential) diagnosis and treatment options as well as scientific and other external references regarding the vast majority of medical conditions encountered in general practice. The Danish doctor manual has been based on the Norwegian doctor manual (NO: “Lægehåndboken”; only accessible by health professionals). Given more than 200,000 unique visitors per months (approximately 10x the number of general practitioners in Denmark), obviously, laypersons are also accessing this resource heavily. In Mol’s (2008): “Doctoring is not something that only doctors do.”

While we arrived at this conclusion simply by considering numbers, this phenomenon is reflected in our data on the hyper-connected Danish citizen. Internet penetration among the Danish population is one of the highest in the world, while the cost of ubiquitous mobile internet access is negligible when normalized w.r.t. buying power. As a consequence, we observe that the first step in individuals’ strategies of health management often is to perform an online search based on symptoms or keywords.

This habitus opens the door for laypersons to also access resources addressed to health professionals, such as doctor manuals or medical research articles, as these routinely show up highly ranked in such searches. Given the official nature of the doctor manual, the health information presented therein appeals strongly to individuals concerned about the quality of sources as well as to those deriving a feeling of empowerment from gaining access to such formerly “sacred” information. In this way, information
resources like the Danish doctor manual nearly accidentally sneak its way into the consciousness of the hyper-connected individual, over time becoming a standard tool in their health management.

Having access to health knowledge on this level allows new empowered behaviour such as, for example, preparing for and checking up on interactions with health professionals online. In the words of 31-year old Lone, customer-service representative from a major Danish city:

*If I am doubting a doctor’s opinion, there are a lot of ways to just check on it. And the first thing I do, I just open the doctor manual [in the browser]. Very comfortable. There is everything: diagnosis, symptoms, and treatment process described very well and understandable. It contains the same information a doctor uses to address standard diseases! It details all the procedures. It tells what to check for and what to prescribe. All there! So, why should I not trust it? If a doctor does something completely different, at least I should doubt very much his opinion.*

The mechanism by which many informants place trust into the doctor manual is analogous to Luhmann’s (1989) idea of trust being transferred from trusted systems to individuals, although the entity receiving the trust in this case, the doctor manual, is another jointly-built institution rather than a single health professional.

Further elaboration of the matter with the informants indicates that this transferred trust is amplified by the fact that the doctor manual is perceived as encompassing the consensus of a large number of experts. This gives a trust boost compared to an individual health professional, as many contemporary patients are well aware that no single person can any longer be an expert on a broad spectrum of medical topics. In particular, patients with a higher educational background seem to approach expertise embodied in single persons with rather large scepticism. This kind of trust boost was rather unexpected as we presumed that such effects would be outweighed by the fact that the individual health professional in a consultation considers the individual case of the patient instead of the necessarily less specific general considerations in the doctor manual.

The access to the health information provided by the doctor manual increases the patient empowerment dimension of “patient education”. Beyond this obvious observation, the access to the doctor manual also enables patients to prepare for interactions with health professionals, as well as to check up on their decision-making process. In other words, it also increases the empowerment dimensions of “patient participation” and “patient control”.

Asked whether she also uses the Danish patient manual, Lone strongly rejects this possibility based on a perceived added value of the doctor manual:

*Not really. I do not read it [patient manual] often. It is just a dumbed down version. […] There is not enough information about which medicine to take. It is not made for doctors, so it is primitive. I need deeper understanding to be able to take decisions. […] I need manuals for professionals, especially, if I should be responsible for my and my family’s health.*

These and similar attitudes are indicative of a desire to increase one’s perception of control by taking over responsibility and, consequently, decision making as well as a desire to educate oneself based on advanced health information. Interestingly enough, information sources officially sanctioned by the same authorities seem to receive different levels of trust, depending on both their contents and their stated audience.

In this first story, we observed a particular side effect of the hyper-accessibility of e-scape medicine: the transfer of the day-to-day burden of health management from health professionals to patients. Public health systems, by making health information hyper-accessible, are shifting the day-to-day burden of health management to the individual, enforcing a “morality of self-control” (Askegaard et al., 2014) with respect to health issues. This kind of self-control can be seen as the logical extension of the “mutual or lateral surveillance” observed in §2.2 of the Online Manifesto and as an instance of Floridi’s (2015) “distributed morality”.

This is analogous to a trend that has already been observed with respect to chronic conditions. Feste (1992) observed that health professionals are “focused on ‘fixing’”, but chronic conditions like “diabetes cannot be fixed”. She concluded that w.r.t. managing with a chronic condition, the “day-to-day burden falls on the patient.” This realization has given rise to a plethora of “living with …” programs that aim
to support individuals with chronic conditions, with Reynolds et al. (2018) identifying “self-management support” as the most frequently used element in chronic disease management.

**Leaving the safe harbour**

While individuals make use of officially-sanctioned health information, their habitus of googling for symptoms and keywords is in no way limited to such information sources. Floridi (2015b) observes that data “now tend to reside and multiply in a multitude of repositories and sources, thus creating and empowering a potentially boundless number of non-state agents, from the single individual to associations and groups”. And indeed, individuals seem to be driven by a strong desire for immediate access to health information from all kinds of sources to fuel their empowered behaviour.

In some cases, this desire is strong enough to override common sense, as for example in the case of Martin, 29 years-old IT-specialist from a major Danish city. He appears healthy and sportive and has no history of allergies or other intolerances. In the following excerpt, Martin describes an experience he had after returning from a two-week trip to Italy:

*I went to Italy with my Italian girlfriend, and we were living two weeks with her family. You cannot imagine what it means to spend time in a traditional Italian family if you haven’t experienced it. You have to eat all the time. A lot of wonderful food. But all the time.*

The experience was not all wonderful, though:

*I’m not used to eating so much white bread. I am a Dane, I grew up on rye bread. And you know Italian kitchen – pizza and pasta, it is a lot of white bread! And it is, of course, very high in gluten. After some days I started to notice that my stomach is bloated all the time, and a couple of times I had bad toilets [diarrhoea]. And, of course, I started to suspect that it might be the gluten. My body is maybe not tolerating so much gluten.*

Asked why he thinks so, whether he has been diagnosed with celiac disease or another form of gluten sensitivity, or someone in his family, Martin answers:

*Of course, not. But I have been googling for my symptoms. And all who have this gluten intolerance, they are having the same symptoms as me. Bad stomach when eating pasta and white bread. Of course, I started to suspect that I am gluten intolerant. And I had to take some action. So, I tried to eat as much as possible vegetables and avoid gluten while I have been in Italy. And when I came home, the first thing I did, I went to the supermarket and bought a gluten-free bread mix and gluten-free pasta and started to produce my own bread. I have to get rid of gluten!*

In a follow-up conversation a couple of months later, Martin reported that while he felt better on a gluten-free diet than he had while in Italy, he dropped it after a couple of weeks and observed no symptoms when eating food rich in gluten. He adopted the more likely explanation that he just ate too much food, in particular food rich in fat and carbs, which he usually avoids in his diet.

This experience demonstrates a shift in the habitual practice of the hyper-connected individual, used to continuously “google” every aspect of their life. Instead of waiting for symptoms to develop or disappear and contact a health professional in the former case, hyper-connected individuals like Martin immediately turn to the abundance of health information available online. In this way, e-scaped medicine is perceived as a more available and rather trustworthy support for episodes of acute but non-life-threatening medical conditions.

In this second story, we observed how the immediate access to health information online, often informally referred to as “Dr Google”, is disturbing the trust balance in the medical system, empowering individuals to take over responsibility for their health, and creating new practices in the day-to-day management of health. In analogy to §3.3 of the Online Manifesto, flows of health information lead to an emergent reengineering of “ownership, responsibility, privacy, and self-determination” in health care.

**It “HIT” me!**

The first two stories highlighted the effects of hyper-accessibility on the consumption of online health information. In our third and final story, we broaden the perspective to the context of online health
communities, where hyper-connectivity allows individuals to find together in order to consume and produce alternative bodies of health-related knowledge. We take onset in an online health community dealing with histamine intolerance (HIT).

HIT in the narrow sense is a condition caused by a deficiency of the enzyme diamine oxidase, which degrades histamines and is normally produced in sufficient amounts by the human body. In the broader sense, HIT covers over a spectrum of conditions, in which the human body reacts strongly to histamines ingested as part of everyday diet.

HIT is an interesting condition to study for two reasons. First, it is a rather new diagnosis, which is not universally established. Consequently, individuals suffering from this condition are natural candidates to feel a lack of support from the public health system. Second, it is starting to become a fashionable direction in the “free from …” food market.

Beyond the use of online health information, no matter whether officially sanctioned or not, an increasing number of patients are beginning to “produce health knowledge” (Nettleton & Burrows, 2003), in extreme cases even going as far as inventing new successful treatments against the medical establishment’s resistance based on self-breeding of and self-infection with hookworms (Broadhurst et al., 2010). These processes often start in online health communities, where patients group either by similar symptoms or shared diagnoses – be the latter official or self-proclaimed.

Floridi (2015b) elaborates on this struggle for information supremacy by arguing that public health systems try to maintain their monopolistic role no longer just legally “but now also economically, on the basis of” their power over the majority of health professionals, as they tend to be employed by state organisations. This argument does not consider the large percentage of citizens researching and producing health knowledge online, though. Thus, we would claim that it is just a matter of time until the state will have to admit that the struggle on informational supremacy has long been lost.

Food intolerances are a prime example of a health-related topic which has become an increasing focus point in the mind of the public, facilitating both research and production of knowledge on these conditions. Particularly gluten and lactose intolerance are among the most established and recognized diagnoses, with supermarket shelves in many countries filled with gluten-free and lactose-free products. A less established, but trending food intolerance is histamine intolerance. The food industry has been fast in picking up on the demand, and free-from histamine variants of some foods notoriously rich in histamines such as red wine have already become a commonplace sight in food retail.

In Denmark, a union of histamine intolerant patients (DK: “Histaminintoleranceforeningen”) has been established in December 2012. This patient union can still be considered grass-roots, non-professional, run by patients for patients - in contrast to the professionalized patient unions described by Ganascia (2015).

At the conclusion of the online fieldwork, the union’s Facebook group featured 631 members, primarily from Denmark, but also including members from other Nordic countries such as Sweden. Even though individuals are collected under the common heading of histamine intolerance, this group was rather diverse with a recent poll listing 48 possible intolerances. The most common answers among the informants to this poll were histamine intolerance (177), gluten sensitivity (not celiac disease, 87), and milk protein intolerance (67). It is important to keep in mind that it is not known how many of these intolerances have been clinically diagnosed.

The desire to (finally) obtain a diagnosis for their symptoms is at the forefront for many new members, such as for example 25-year old Louise (A), pedagogue from a medium-sized Danish town, who engages with an established member (B) of the group on the topic of testing:

A: Hi. I am new in this group and the word histamine intolerance is quite new for me. I have some questions I hope you can help me with: How can you get tested for it? And by who? I’ve once taken a Vega test [a form of electroacupuncture], which showed a lot of things, my body didn’t like. Is that result the same as histamine intolerance?

B: I was tested by a Dutch lab, KEAC [Center for Environmental Medicine].

A: A bit tiresome one can't be tested in this way in Denmark. But thinking it might be a bit like a Vega test?

B: This here is a regular blood test.
Louise is prepared to take things into her own hands and to learn about a diagnosis that she believes might apply to her health situation. The conversation is joined by another rather new member (C):

C: Is it your own doctor taking your blood and sending it to the Netherlands? Could one risk that the doctor will not do it?

B: Go to their website and order a test set. I then got my doctor to take [blood] samples, sent them myself, so it was easy enough. I don't have a clue whether all doctors are willing to do it. But why would they say no? Otherwise, I guess you know a doctor or two in your social circle - or a nurse.

These individuals are making use of the services of different health systems, designing their own amalgamated diagnosis strategy. This can be seen as an empowered approach to diagnosis, where the general practitioner is demoted to a support role regarding the taking of a blood sample. Trust is distributed in an interesting balance between “oneself”, “jointly-built institutions” and communities.

Based on this new balance and the knowledge exchange through the online health community, many individuals are supported in establishing a counter-expertise w.r.t the health profession. Often, they are even encouraged to produce their own health knowledge.

Other members such as (D) advocate exclusive trust in “oneself”, resulting in a fully independent empowered self-diagnosis strategy based on performing trial-and-error elimination diets:

D: You can also try to avoid foods rich in histamines. It showed me right away that it was HIT [histamine intolerance]. It became better by the day when I avoided histamine. I have never been tested by KEAC.

Instead of a clinical test in the background, individuals seem to rely on their bodily experiences, observing their reactions and feelings and trusting themselves. This form of self-diagnosis obviously bears the risk of confusing causation with (accidental or systematic) correlation. From monitoring the group for a few years, it can be concluded that a large part of the membership has not been clinically diagnosed. This implies that advice on histamine intolerance is very likely given to trusting new members by established members who are actually able to tolerate histamines.

Indeed, it may seem surprising how fast new members of the group are starting to trust the online community and, consequently, the other members of the group. To understand this phenomenon, we need to consider that these individuals have suffered from repeating symptoms and a self-perception of being sick for an extended period. This lived experience results in two outcomes regarding their trust pattern, that catalyse each other.

First, observe that these individuals have been unable to obtain satisfactory support from the public health system. They have been unable to effectively cooperate with the health system in order to solve their problems. They feel rejected, as they typically have neither received an official diagnosis nor successful treatment of their symptoms.

Second, by suffering for an extended period without any clues regarding whether their conditions are going to deteriorate, improve or stay the same, they find themselves in an unpredictable and anxiety-inducing situation. In other words, in a situation where they have a desire for being able to allocate more trust.

In combination, they are losing trust in the public health system while being inclined to allocate trust to some entity, where they feel accepted and they see a potential for obtaining support. It is well-known that individuals that have gone through a “similar experience” in “the same stage of life” can trust each other easier and faster as they do “not have to undergo as extensive a perspective-building process” (Weber & Carter, 2003).

In addition, the mechanism for trusting the members of the group is amplified by the effects described in Luhmann’s (1989) theory. Initially, trust is built in an assessment of the trustworthiness of the group and the underlying patient union. Then trust is transferred from this trusted system to the members of this group.

While at the forefront for many users, it is interesting to observe that obtaining a clinical diagnosis is by far not the only motivation to engage with the online community. Another commonly found theme is
that of “not being alone”, i.e., of being recognized as a sufferer by other individuals with similar symptoms. Here, another new member (E) expresses this explicitly in her first post:

_E: How am I both delighted and dismayed to have found out that I have histamine intolerance. There's so much to read and too little you can actually eat, so I haven’t really started properly yet. It all started after my last pregnancy and appears in the form of hives, red spots, extreme itching, and bad mood. I wonder whether it can show up due to something hormonal. No matter what, thank you for this group. It's nice to know you’re not alone. Is there by the way anybody who knows whether HIT can be hereditary?_

When another member (F) inquires how she obtained that diagnosis, it becomes apparent that what is most important for (F) is to receive confirmation for her diagnosis. In the absence of a clear clinical diagnosis, this confirmation is alternatively obtained through recognition, acceptance and attention from the community:

_F: How have you found out about it - through a blood test?_

_E: No, I had read that one could not be tested for it? I have an increased histamine level in the body. Have therefore tried to exclude things from my diet but couldn't figure out what I reacted to. And then I found HIT, and it all suddenly made sense._

Many members of this online community are in the same situation. They could not receive the kind of support that they were looking for from traditional interaction with health professionals. By googling for their symptoms or describing them in online interactions with acquaintances they find online communities, where members have similar histories and symptoms.

In particular, in the case of being recommended to an online community by an acquaintance, the trust to their “neo-tribe” results in a relatively high initial trust to this community. Consider also that these individuals are lay people, typically not trained in differential diagnosis. In their perception having similar symptoms is often enough to “adopt” other members diagnoses nearly instantaneously. Finally, they are motivated to this “adoption” as this brings them closer to the recognition as a sufferer and the following attention, sympathy and respect that they are missing and direly seeking.

In our netnographic research, we also encountered more reflective voices among the members of the online community. A piece of more careful advice on self-diagnosis by matching symptoms is for example given by a male member (G) of unknown age and profession from Stockholm:

_G: Same here. A little advice on the way is not to listen too much to others (for example such a Facebook group) because the advice is highly dependent on the individual and cannot be translated directly into your own situation. If one trusts too much in other people's advice and reads too much by oneself, and fill in one’s head with knowledge, it can be like jumping into a pool of worms/snakes. That on its own can make you believe that you have a lot of symptoms you don’t actually have. Blood tests performed by for example non-serious pseudo doctors/healers, often give a result that will primarily benefit them and not you. Research is very immature, and the actual approved practices are very few._

Member (G) also provides explanations for individuals’ tendency to self-diagnose by matching symptoms:

_G: The individual's willingness to make sense of their problem is stronger than the opportunities of current science to support them, which creates this amount of information on the internet based on copying and pasting other people's experiences. Bottom line: don't react to everything that other individuals are writing or on what you are reading. Keep calm._

In this story, we observed how hyper-connectivity catalyzes a process of health knowledge production in a context, where the established medical authorities do not (yet) provide the biomedical and social support needed by the sufferers. In this vacuum, the counter-expertise established in the interaction of the hyper-connected individuals has an original character, transcending the existing health knowledge and strengthening the empowerment dimension of “patient autonomy”.

Online communities such as the one studied here seem to naturally bridge the “distinction between public and private” (Online Manifesto §3.6), providing a sense (or at least an illusion) of “intimacy, autonomy, and shelter from the public gaze” (§3.7), while allowing for “a range of interactions and engagements that incorporate an empowering opacity of the self, the need for self-expression, the
performance of identity” (§3.8). These communities provide support to their hyper-connected members, not only regarding biomedical but also regarding social needs.

**Hyper-connected health communities – curse or blessing?**

In the last decade, arguably humanity has continued their journey towards hyper-connectivity at breath-taking speed, leading to “major changes in the scale and nature of individual relationships”, and consequently to a “dramatically evolving” social fabric (Ganascia, 2015). Most of Johnson and Ambrose’s (2006) nine limitations have been overcome by the accelerating technical and socio-cultural development. In the following three paragraphs, we shortly contrast the current state of affairs we encountered with the situation one decade ago regarding the first six of them. Then we examine our findings in the light of the remaining three limitations, reflecting on the blurring lines between normality and pathology as well as between privacy and publicity in our networked society.

*Access* to technology has become nearly universal, with low costs and ubiquitous (mobile) internet access. *Ease of use* is likewise a diminishing problem, with even the oldest generation routinely accessing online resources through smartphones and tablets. *Fragmentation* of communities continues as a phenomenon but given that close to half of the world’s population have immediate access to the internet, there are sufficiently many sufferers to reap the benefits of scale even in a fragmented setting.

Likewise, *authentication and accountability* no longer pose a challenge with centralized authentication solutions via social media providers applicable where desired. Fragmentation and the possibility for anonymity cannot be controlled given the nature of the technologies underlying hyper-connectivity. This is not necessarily negative, as fragmentation gives the possibility to build new communities if existing ones are not satisfactorily, and the use of anonymity continues to have its function given the sensitive nature of many health issues discussed in online communities.

Concerns about *commercialism and privacy* as well as *safety and security* persist and have possibly grown more prominent, but this is not limited to applications of online communities in health care. The data produced in the exchange between hyper-connected individuals in online communities, on social media and elsewhere has become the raw material fuelling a data analysis industry worth hundreds of billions of dollars. The struggle for privacy and security has become a part of the hyper-connected individual’s everyday life.

Johnson and Ambrose’s (2006) concerns about online communities contributing to the creation of a *generation of hypochondriacs* seem very relevant today. Statements of their informants such as that “*it feels good to know I am not alone and that I can share and learn with you all*” were encountered in nearly the same words also in the data used in this chapter. Their hope that “the interaction with real patients in communities may actually serve to reduce hypochondriasis and keep hypochondriacs from wasting valuable medical time and resources” seems to have been taken over by the amount in which hyper-connected individuals immediately resort to online information in all possible situations of life. The second story we presented is a typical illustration of this phenomenon.

The data underlying this chapter hints rather at a blurring of the lines of normality and pathology. With immediate access to health information that allows individuals to self-diagnose themselves whenever they encounter some physical or mental condition they feel is out of the ordinary, it can be argued that we are all becoming hypochondriacs. A bloated stomach is more than sufficient to self-diagnose as being gluten intolerant, and even start self-treatment. Hyper-accessibility and hyper-connectivity seem to be turning us all into potentially self-diagnosed sufferers, or hyper-connected hypochondriacs. White and Horvitz (2009) have coined the term “cyberchondria” for this phenomenon, where self-diagnosis based on online searches supplements traditional interaction with professional health care.

This can be seen as an instance of the proliferation of Parsons’s (1951) “sick role” caused by the growth of medical evidence and diagnostic abilities. Citizens that would have been considered healthy before can now be considered sufferers. This development has been escalated by advances in genetics that “open up the possibility of defining almost all of us as sick, by diagnosing the ‘deficient’ genes that predispose us to disease” (Moynihan & Smith, 2002). The role of health professionals has accordingly been undergoing a transformation from “tamers of death” to “managers of the living” (Arney & Bergen, 1984).
Health professionals concerns about misinformation being spread by patients through online communities have surely proven to be well founded. Ganascia (2015) even reports on a case, where health professionals have intentionally spread misinformation in order to counteract unfavourable policy. Our research rather suggests misinformation from patients should not be attributed to malice, though, but rather to individuals’ lived experience of not being treated satisfactorily by the established health system. When sufferers have found “their” diagnosis by turning for help to others in similar situations, they, in turn, feel a desire to “give back” to the community by helping others, who are perceived to be in similar perils.

Low awareness of the potential for misinformation paired with low regard for the “first do no harm” maxim underlying modern Western medicine results in a rather undiscerning use and spread of information. Ganascia (2015) postulates that the networked society has an “epistemic responsibility” to “condemn the dissemination of wrong knowledge”. His rather idealistic idea of the establishment of some kind of “ethical control” of information seems unrealistic given the inherent lack of control over content on the internet and the perseverance of many of its users. Or as one member of the Facebook group on histamine intolerance answers to a voice of reason and caution (member G from above): “Good advice is rarely appreciated”.

Rather than being judged on the merits of its contents, a piece of advice seems to be evaluated based on trust in the adviser. And the situation regarding who or what to trust has indeed changed considerably in the lights of hyper-accessibility and hyper-connectivity. While it may be true that “for some, the trust-building potential and assurance of a face-to-face dialogue may never be replaced with impersonal digital interaction”, we found many individuals that trust more in “Dr Google” and online health information (both officially-sanctioned and user-generated) than in individual health professionals.

In particular, in the case of online communities, legitimacy to each other seems to be of higher concern than duties to society. Underlying this development, we find the desire of the individual to be recognized as a valid sufferer and thereby a member of the community as well as to receive respect, attention, and sympathy from other members. By becoming a member of the community, the other members of the community become part of the individual’s neo-tribe. This allows keeping health-related topics in a private sphere that has been extended to online interactions in health communities. This is in line with Ess’ (2015) concept of “public privacy’ in online venues, as a third space between purely individual privacy and indiscriminant publicity” rather than Thorseth’s (2015) blurring of “private and public”, which she views as “complementary categories” rather than “counterparts”.

The on-going and socially supportive medical dialogue available from an online community in this third space cannot be provided by point interactions with health professionals. In general, trust can be seen to move from classical “jointly-built institutions” and their accredited members to “oneself” and one’s “neo-tribe” as a result of both hyper-accessibility and hyper-connectivity. Our findings on trust can be regarded as examples of what Ganascia (2015) coins the “shattering of institutions”. The changing balance of trust we encountered is arguably disruptive to the legitimacy and, thereby, the core of established institutions.

**Hyper-connected hypochondriacs or empowered knowledge producers?**

On the ruins and shards of Ganascia’s (2015) “shattered institutions” rises a new type of patient – the hyper-connected empowered individual, enabled by hyper-accessibility, willing to take over responsibility for their health, to use their freedom of choice to create new forms of diagnosis and therapy or combine existing ones. While partly forged in the fires of neoliberal reforms aimed at empowering patients as a means of offloading health professionals (Salmon & Hall, 2003) and optimising resources (Anderson, 1996), these individuals transcend the intentions behind these officially-sanctioned empowerment efforts and become producers and disseminators of new health knowledge. In our final section, we reflect on this redistribution of medical responsibility and the ensuing implications for the power relation between the individual and society at large.

Observing the new type of bottom-up empowered hyper-connected patients leads us to reflect on what empowering patients really means. Are patients that are targeted by top-down empowerment programs actually empowered, or are they just forced into a role, where they need to take over the day-to-day burden of managing their health? Or in terms of Simon’s (2015) distinction between “being responsible”
and “taking responsibility”, we would argue that they are just “being responsible”. And are the bottom-up empowered hyper-connected individuals we encountered really “taking responsibility” by looking for a (bio)medical solution to their problems as patients, or are they motivated by broader socio-cultural needs as humans?

Top-down empowerment has been criticized, e.g. by Salmon and Hall (2003) as “a professional construction: it existed in the minds of clinicians and researchers and did not reflect patients’ experience”. On the structural level, (Greeener, 2008) has questioned the neo-liberal and “high modern assumption” (Ess, 2015) of patients as rational agents or “Hombres oeconómicos” underpinning most organized empowerment efforts, i.e., the account of the self as “being autonomous, disembodied, rational, well-informed and disconnected” (Online Manifesto §4.1). Floridi (2015b) argues that the democratisation of data “is generating a new tension between power and force, where power is informational and exercised through the elaboration and dissemination of norms, whereas force is physical and exercised when power fails to orient the behavior of the relevant agents and norms to be enforced.” Taking this perspective to the extreme, being empowered would be a direct consequence of being informed well enough to make rational decisions. In contrast, we find that being empowered additionally requires the willingness to take responsibility.

The doubts regarding the rationality of patients are fuelled by Kristensen, Askegaard, Jeppesen, and Anker (2010), who find that individuals are guided by bodily feelings and reactions regarding health questions. Our intensive and extensive exposure to the exciting world of hyper-connected empowered patients and hypochondriacs leaves us with a perception that immediate behaviour, based on feelings and hard to predict from the outside, is more the norm than the exception. The dual perspective in §4.1 of the self as “an object of enquiry among others” and “fully analysable and predictable” seems to be an ever-moving target in much the same way as the “omniscience/omnipotence” posture in §3.3. Many participants of online health communities seem to be using them as much as a tool to gain recognition, attention, acceptance, respect and sympathy than as a tool to solve their health problems. This tendency seems to be particularly pronounced in cases of long-lasting or chronic but non-life-threatening symptoms.

That online communities can deliver this kind of mental support is in line with earlier studies measuring the effect of online communities on interpersonal support – see e.g. Eysenbach, Powell, Englesakis, Rizo, and Stern’s (2004) meta-study on online health communities and support groups. The increased perceived social and, in particular interpersonal, support when using online communities was found to be statistically significant in all studies that featured a rigorous statistical analysis. Likewise, we advocate viewing online health communities as a less formal pendant of patient associations, instantiating their original goal of networking between peers with similar health-related needs. This view supports Ganascia’s (2015) ideas regarding the establishment of “new forms of solidarity that emerge in a networked society” as a result of hyper-connectivity.

Taking a step back and broadening our perspective from the individual to the society at large, we reconsider the implications for Parsons’ (1951) social sick role, where sufferers are excluded from the demands of society. This aspect of the sick role has long been criticized in the context of chronic diseases (Varul, 2010), and an exclusion from society’s demands seems even more problematic in light of both the potential to diagnose nearly anyone as sick and the hyper-connected hypochondriacs’ tendency to do so themselves.

We argue that the medical knowledge and the social support resulting from hyper-accessibility and hyper-connectivity are giving birth to a new form of empowerment, one that is less rational and more social than the neo-liberal variants promoted by the institutions of modernity. One where a patient’s individual needs, be they physical or mental, and their desire to overtake responsibility determine the course of action independent of the professional health sector’s predetermined one-size-fits-all (bio)medical services and solutions.

Embracing this form of empowerment requires an acceptance of Friedrich Hayek’s kosmos rather than taxis (Online Manifesto §3.5), i.e., of supporting “natural” development rather than holding on to planning and control (§2.1). It should be seen as a chance to increase inclusion instead of exclusion of sufferers, to transition to a state where instead of excluding sufferers from societies demands, sufferers place demands on their surrounding societies. A state where we return to the principles of “reciprocity and recognition” originally underlying Parsons’ (1951) social sick role, where freedom occurs “in a space of affordances and constraints” (Online Manifesto §4.2).
References


Varul, M. Z. (2010). Talcott Parsons, the Sick Role and Chronic Illness. *Body & Society*, 16(2), 72–94.

