Mental Health Online

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The enactment of expertise on bipolar disorder on American and French online platforms

Claudia Egher

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Mental Health Online

The enactment of expertise on bipolar disorder on American and French online platforms

DISSERTATION

To obtain the degree of Doctor at Maastricht University,
on the authority of the Rector Magnificus, Prof. Dr. Rianne M. Letschert
in accordance with the decision of the Board of Deans, to be defended in public
on Wednesday 4th of December 2019 at 12:00 hours

by

CLAUDIA EGHER

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References

LIST OF ACRONYMS AND ABBREVIATIONS

AA	Alcoholics Anonymous
AI	Artificial Intelligence
AIDS	Acquired Immunodeficiency Syndrome
APSA	L'Association des Psychotiques Stabilisés Autonomes
BPS	British Psychological Society
CESE	Conseil Économique Social et Environnemental
CNSA	Caisse Nationale de Solidarité pour l'Autonomie
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
DTCA	Direct-To-Consumer Advertising
EBM	Evidence-Based Medicine
ECT	Electroconvulsive Therapy
E-FOIA	Electronic Freedom of Information Act
EIT	Electronic and Information Technology
EMDR	Eye Movement Desensitization and Reprocessing
ERCIC	Ethical Review Committee of Inter-City Faculties, Maastricht University
GDP	Gross Domestic Product
GDPR	General Data Protection Regulation
GEM	Groupes d'Entraide Mutuelle
GIA	Groupe d'Information Asile
GP	General Practitioner
HAS	La Haute Autorité de Santé
HIV	Human Immunodeficiency Viruses
HONcode	The Health of the Net Foundation Code of Conduct

ICD-10	The International Classification of Disease and Health Related Problems, 10th edition
ICT	Information and Communication Technology
IE	Interactional Expertise
ISO	International Organization for Standardization
KTRO	Radio Station Licensed to Transmit in Portland
LFB	Le Forum des Bipotes
NAC	N-acetylcysteine
NIMH	National Institute of Mental Health
PDF	Portable Document Format
PXE	Pseudoxanthoma Elasticum
OECD	Organization for Economic Co-operation and Development
RGAA3	Référentiel Géneral d'Accessibilité pour les Administrations
SAD	Seasonal Affective Disorder
STS	Science and Technology Studies
SEE	Studies of Expertise and Experience
U.K.	The United Kingdom of Great Britain and Northern Ireland
U.S.	The United States of America
VNS	Vagus Nerve Stimulation
WAI	Web Accessibility Initiation
WCAG	Web Content Accessibility Guidelines
WHO	World Health Organization
W3C	World Wide Web Consortium

LIST OF TABLES AND FIGURES

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UTOPIA

Island where all becomes clear.

Solid ground beneath your feet.

The only roads are those that offer access.

Bushes bend beneath the weight of proofs.

The Tree of Valid Supposition grows here
with branches disentangled since time immemorial.

The Tree of Understanding, dazzlingly straight and simple,
sprouts by the spring called Now I Get It.

The thicker the woods, the vaster the vista:
the Valley of Obviously.

If any doubts arise, the wind dispels them instantly.

Echoes stir unsummoned
and eagerly explain all the secrets of the worlds.

On the right a cave where Meaning lies.

On the left the Lake of Deep Conviction.
Truth breaks from the bottom and bobs to the surface.

Unshakable Confidence towers over the valley.
Its peak offers an excellent view of the Essence of Things.

For all its charms, the island is uninhabited,
and the faint footprints scattered on its beaches
turn without exception to the sea.

As if all you can do here is leave
and plunge, never to return, into the depths.

Into unfathomable life.

Wisława Szymborska

Szymborska W. (1998) *Poems. New and Collected 1957-1997.* Orlando: Harcourt Inc. (Trans. Stansisław Barańczak & Clare Cavanagh).

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Chapter 1

Studying expertise online

CHAPTER 1

1 STUDYING EXPERTISE ONLINE

Her left index finger was about to touch the keyboard, when a tide of memories from five years ago rose and flooded the sentence Janice's thoughts had so painstakingly patched together. Walking home that day she could vividly remember the rather eerie feeling she had experienced staring intently into people's faces, trying to make out from the mysterious maps that wrinkles had drawn on them what kind of emotional states they were most prone to, wondering how frequently they had questioned their own sanity. She'd stopped on her doorstep, looking rather apprehensively at her front door, as if some long-lost truth she'd been searching for all this while was finally about to reveal itself on its shiny surface. Was the person who'd left the house that morning on the way to the doctor's appointment the same as the one who was about to enter? The diagnosis hadn't really come as a surprise, yet those two sticky words had turned her life into a before and after, no matter how she chose to qualify that rupture. And how was she to handle such a truth, if truth it was? She'd almost stumbled on her way to the computer — another shiny surface she was hoping was more inclined to provide conclusive answers.

Five years later she would find herself the center of an irregular galaxy, with numerous online applications gravitating around different areas in her body, cornering her bipolar disorder into temporary submission. While some digital technologies were harvesting data from her, other applications ensured that she was constantly in touch with many different people. She received regular online advice from professionals who may have never set foot in a medical school or even seen the gates of a college, for all that she knew, and was notified in real-time about the appreciations her own insights had received and the questions they had given rise to. She liked to take stock of such reactions, but in time she found that she could hardly keep up, struggling between an endless chain of notifications, countless invitations for study participation, and kind reminders to evaluate mental healthcare providers, who hadn't all been that kind.

She couldn't tell for how long she'd been staring at the empty white rectangle where her reply was due, when the doorbell rang. What could she advise that French young father whose son had just been diagnosed with bipolar? What had she actually learned during these five years of intense online participation? And how much of that would still hold when removed from the American context? The beginning of a smile withered on her face as she turned the key in the lock. It wasn't on doors that one was shown who one was these days. For what *surface, no matter how shiny and dust-free, could be a better mirror than one's results page on Google? What could be more confrontational, yet seemingly more innocuous, than a set of answers wrapped in a bubble of one's own creation, woven from one's interests, clicks, and gaze when safely at home, at ease?*

This vignette raises a number of questions which are at the heart of this dissertation, as it indicates that a mental condition is not only a biological, but also a social entity, and as it points to some of the ways in which the internet has shaped the enactment of expertise about bipolar disorder. This study sets out from the premise that the internet has contributed to new challenges and opportunities in the enactment of expertise, for people like Janice, who have traditionally been relegated to the position of "objects of knowledge", for those who have historically enjoyed expert status, such as medical professionals and official institutions, as well as for new categories of stakeholders that come into existence. The internet has facilitated the "participatory turn" (Prainsack, 2011) in healthcare, with a plethora of online platforms and mobile health applications claimed to disrupt the traditional distribution of knowledge and power between medical professionals and people diagnosed (Dedding et al, 2011; Eysenbach et al, 2004). Yet, the term "participation" has turned out to be rather vague (Nielsen & Langstrup, 2018; Wyatt et al, 2013), and it is not clear how active such involvement with one's health is or should be, nor whether participation reaches as far as allowing people diagnosed to contribute to the production of knowledge, and what such contributions consist of. It is therefore uncertain whether the internet allows for people diagnosed to re-position themselves in relation to medical professionals and to play a more active role in the evaluation and production of knowledge.

What is clear is that the internet has provided new avenues for more individuals like Janice to acquire information (Ilic, 2010) and to thereby become more knowledgeable about their condition. Furthermore, this medium has also been praised for enabling people with similar concerns and interests to come together and exchange insights. Yet, how the internet shapes the online enactment of expertise at the level of individuals or groups and whether it also helps give rise to new configurations still needs to be studied empirically. Additionally, the internet can also influence the performance and transmission of local norms and values, which is important, since knowledge on mental health carries numerous cultural markers**.** Nevertheless, Janice is not alone in wondering how distinct cultural perspectives inform online exchanges about bipolar disorder, as surprisingly little is currently known about this topic. This study addresses these different aspects by asking the following research question: How is expertise about bipolar disorder enacted on American and French online platforms? It is guided by four sub-questions, with the elements highlighted in these paragraphs functioning as building blocks towards a satisfactory answer: (1) How do different stakeholders engage with online technologies to enact expertise about bipolar disorder? (2) How does the use of internet for processes of knowledge evaluation and production allow for people diagnosed with bipolar disorder to re-position themselves in relation to medical professionals? (3) How do cultural markers shape the online enactment of expertise about bipolar disorder? (4) What individualizing or collectivity-generating effects does the internet have in relation to the online enactment of expertise about bipolar disorder? In addressing these questions, this study aims to contribute to the fields of science and technology studies (STS), media studies, and medical sociology. A brief overview of the public and theoretical debates that have informed these particular questions and information about how they are addressed in the chapters of this dissertation are presented below.

Over the last decades expertise has had a rather paradoxical trajectory. One may argue that at no time in history has expertise been so prevalent as it currently is in Western society, having infiltrated various aspects of one's life, from child-rearing and health to interior design, lifestyle choices, and personal savings. From this point of view, expertise has expanded and now covers areas for which no specific and substantial knowledge was previously thought to be necessary, and expert opinions are called upon for an unprecedented variety of issues. Yet, while this suggests that expertise has become ubiquitous as well as highly valued, the identity of experts, of those who can be rightfully called upon to provide authoritative answers and solutions to complex, "wicked" problems has been challenged. In general, these challenges have been informed by two important developments. On the one hand, highly mediatized controversies, such as the one surrounding the "psychological warfare between therapists and scientists" (Tavris, 2003:7) surrounding the introduction of evidence-based practice in mental health (Tanenbaum, 2005), have increased public awareness about important disagreements that often exist among experts and about the conditions of uncertainty under which they make recommendations and decisions. This has served to weaken the cognitive authority of "traditional" experts. On the other hand, the growing popularity of the internet and the spread of so-called web 2.0 platforms, where users not only consume information, but actively contribute to its production, has facilitated the circulation, accessibility, and visibility of insights provided by many other stakeholders. This has drawn attention to the fact that people lacking official accreditations can also possess substantial knowledge and experience in certain domains. It has also facilitated the production of (alternative) knowledge and the development of new types of scientific collaborations, in different settings, with different tools and involving more diverse groups. This way, the authority, tasks, and obligations of relevant stakeholders have undergone more or less substantial transformations.

These developments have led many enthusiasts to assume the use of web 2.0 technologies will contribute to the so-called "democratization" of science (Kitcher, 2011) by enabling the involvement of stakeholders other than scientists in processes of knowledge evaluation, dissemination, and production (Dickel & Franzen, 2016; Brown, 2009). Yet, these transformations have also been met by heavy criticism, with some scholars and journalists warning against "the death of expertise" (Nichols, 2014) brought about by two main sets of objections to its authority. The first set of objections is based on what is perceived to be a dilution of the substantial character of expertise due to its too broad expansion (Collins & Evans, 2007). The second set of objections focuses on counter-reactions to the so-called "hegemonic" character of expertise, with some critics drily remarking that "people… have had enough of experts" (Gove, 2016). As a consequence, instead of something stable and well-bounded, expertise has come to mean different things to different people: it is acquired and manifested in myriad ways across different locales, it fulfills different functions, and is importantly shaped by social, cultural, and economic factors. This raises important questions about the identity and position of those who can acquire expertise and about the ways in which they enact it, that is, about the practices, tools, and standards through which they articulate it. And this is the main aspect that this dissertation focuses upon.

The processes through which one can develop expertise are domain-specific, as they involve the acquisition of particular types of knowledge and the internalization of relevant practices, norms, and values. In this dissertation, I focus on mental health, where the developments sketched above have had a profound impact, and where expertise has had a particularly convoluted trajectory. This has been the case partly due to the complex and elusive nature of mental conditions and partly to the problematic status of psychiatry in relation to medical sciences. The (relative) success of psychotropic drugs, the development and widespread use of brain neuroimaging techniques and advances in genetics have stimulated in recent years the search for biomarkers for mental health conditions and have contributed to the proliferation and diversification of professionals working in this field. Nevertheless, mental health expertise continues to be challenged, with some critics denouncing it for pathologizing variations in average human behavior (Horwitz and Wakefield, 2007), and others condemning it for medicalizing social and political problems (Metzl, 2009). Furthermore, people diagnosed have assumed an increasingly active role in the production of knowledge about mental health, and not always in collaboration with medical professionals. Nevertheless, the tremendous increase of mental health diagnoses around the world suggests that it is more important than ever to understand how expertise about mental health is currently enacted online, by whom, and through what means.

This dissertation addresses these issues by focusing on bipolar disorder, a mental health condition which has become more prominent over the last decades, and which is currently among the top ten causes of disability worldwide (Whiteford et al, 2013). It is a mood disorder characterized by the alternation of depressive and manic episodes and marked by episode-free intervals. While it is thought to be determined by a combination of neurological, genetic and environmental factors, the precise causes of this condition are currently unknown. It is studied by various specialists: psychiatrists, psychologists, neuroscientists, endocrinologists, molecular biologists, epidemiologists, etc. These professionals focus on different sites as the origin and location of this condition, they use different techniques and materials, and so they understand rather different things by bipolar disorder (Dehue, 2008; Mol, 2002; Hacking, 1995). Furthermore, the therapeutic approaches used for its management consist of diverse combinations of chemical substances, talk and behavioral therapies, as well as technological interventions, such as transcranial magnetic stimulation or vagus nerve stimulation. Dominant approaches in personalized medicine have further enhanced the complexity characterizing this field, as new subgroups have been distinguished among the people diagnosed with this condition based on whether or not they exhibited specific genetic modifications, and on their responses to certain medications. Moreover, these perspectives shape and are shaped by the ways in which people diagnosed with this condition experience it. Bipolar disorder can therefore be seen as a "moving target" (Hacking, 1999), since it mobilizes different types of knowledge, groups of professionals, tools, standards, and methods in dynamic configurations. This makes the study of this condition relevant to the study of expertise, as it can lead to a better understanding of the ways in which expertise is enacted when numerous factors are involved and when a field is marked by numerous known as well as unknown unknowns.

Expertise about mental health has been traditionally enacted in the hallways of medical institutions, in laboratories and clinics, on the pages of compendia and scientific journals. However, since the late 1990s, when the internet began to be widely adopted, the prominence of this medium as a new site for the provision of knowledge and the enactment of expertise has grown (Hu & Sundar, 2010; Fox et al, 2005; Hardey, 1999). This has been particularly the case after the development of web 2.0 technologies, such as social media platforms and wikis, where people could not only consume mental health-related information, but also actively engage in its production. As medical information has become accessible to broad audiences and as people diagnosed have started to play a more active role in the development of knowledge, some scholars thought that the internet would contribute to more equal or balanced relationships between medical professionals and people diagnosed, what some (Topol, 2013; Kitcher, 2011) have referred to as "democratization". While more nuanced studies have since been provided (Versteeg et al, 2018; Ziebland & Wyke, 2012) and while people diagnosed increasingly use digital technologies for various health-related purposes, it is yet unclear what exactly the latter contribute and how these contributions are used. Nor are there many results available on the ways in which the internet has shaped how "traditional" experts enact expertise. This study therefore seeks to contribute to these discussions by asking how different stakeholders use the internet to enact expertise and how democratizing such practices are. Furthermore, by combining insights from media studies on different types of online encounters and their dynamic character with sociological perspectives on the potential of personalized and precision medicine for the development of new types of communities (Stommel & Lamerichs, 2014; Tutton & Prainsack, 2011; Akrich, 2010; Sundar et al, 2007), this dissertation explores the possibility of new individual-group configurations in the online enactment of expertise about bipolar disorder.

Despite attempts to stabilize expertise about mental health, knowledge about mental health conditions is not universal, but depends on the social, cultural, and economic contexts in which it is made manifest (Lakoff, 2005; Kleinman, 1988). Thus, how bipolar disorder is recognized, understood, and intervened upon depends on the ways in which the provision of mental healthcare is organized in any given country, and on the interpretative tools used by professionals. It is also informed by the different ways in which people learn to distinguish and make sense of problematic experiences from the incessant flow of physical and psychological stimuli and reactions that make up their lives. This raises important questions about the fate of such local and cultural markers in the online enactment of expertise about bipolar disorder. To cast some light onto these aspects, this study compares the American and French perspectives on bipolar disorder and use of online technologies in mental healthcare. Given the growing popularity of online platforms among people diagnosed with mental health conditions (Carron-Arthur et al, 2016; Naslund et al, 2016), such findings are very important, because cultural and social elements may influence who feels entitled to share information, what type of information is shared, and how it is subsequently interpreted and put to use by readers. In an attempt to avoid cultural reification, the results of such comparison are presented at the level of each chapter, thus illustrating how various similarities and differences developed as an integral part of the specific analyses conducted.

Through the empirical analysis, this dissertation makes a contribution to the fields of STS, medical sociology, and media studies in ways that I briefly touch upon here. The main finding is that the enactment of expertise about bipolar disorder is not a straightforward process by which offline practices, tools and approaches are transferred online, but involves additional skills and complex negotiations, which sometimes lead to unexpected configurations. The analysis of the empirical materials collected made me realize that the current theoretical perspectives on expertise do not sufficiently account for the complexity of positions that relevant stakeholders occupy and for the different types of relations they need to cultivate to successfully contribute to the development of expertise. That is why I put forward a new approach to expertise, wherein expertise is conceived as a practical achievement, realized through coordination and affective labor among stakeholders who occupy multiple and shifting positions across a complex ecosystem (discussed in more detail in section 1.2). This new approach is arrived at by engaging in dialogue with and building upon influential theories on expertise in STS. In the process, several empirical and theoretical contributions are made. By bringing insights from media studies in dialogue with the recently developed field of Studies of Expertise and Experience (SEE), this dissertation makes a theoretical contribution, expanding the concept of interactional expertise developed by Collins and Evans (2002) (discussed in more detail in the following section) by taking into consideration the effects of the medium through which it is enacted. Building on STS insights on users, this dissertation contributes to medical sociology by showing that through their specific engagement with the online affordances of blogs and fora, people diagnosed with bipolar disorder move beyond the enactment of lay expertise, and put forward what I call "digitally-enabled hypotheses" about treatment effectiveness. This dissertation also makes a contribution to ethical debates on the impact current visions of healthcare have upon certain societal values. Thus, at a time when the current dominant neoliberal model of governance encourages people to take up behaviors illustrative of narrowly-conceived notions of individual autonomy and personal responsibility, the findings presented here show that some people follow up on such encouragements and use the internet to become successful entrepreneurs, while others develop more nuanced approaches, enacting solidarity and contributing to the collective development of lay expertise together with others with whom they share important similarities.

In the remainder of this introduction, I provide an overview of the main theoretical approaches to studying expertise, followed by a brief historical description of the medical trajectory of bipolar disorder, and a discussion of the similarities and differences between the ways in which mental healthcare has been organized in the U.S. and France. I then give some details about the sources and the methodological approach used in this study. The introduction concludes with an overview of the structure of my dissertation.

1.1 Theoretical approaches to expertise

Expertise means different things to different people, it is enacted differently in different contexts, and leads to different relations between people who hold expertise and those who do not as well as between those endowed with different types of expertise. While the Oxford Dictionary first mentions the term "expertise" in 1869, it was not until the

1970s that expertise started to gain considerable academic interest, thereby "reflect[ing] the growth and proliferation of professions with specialized forms of knowledge, and (…) the increased commodification of knowledge production" (McNeil, 1998: 56-57). It has thus far mainly been studied within the fields of psychology, sociology, and philosophy (Young & Muller, 2014), and such forays have been characterized by important disciplinary differences as well as significant distinctions in approach and conceptualization at the level of each discipline broadly understood (Williams et al, 1998). These distinctions have also been prompted by the main problems that scholars have thus sought to provide answers to: the meaning and role of expertise in the context of the democratization of science and the need to (re)consider the specific character of human expertise in light of the more recent rise of "expert systems" and of important developments and ambitious visions developed in the field of artificial intelligence (AI).

The main difference in these diverse forays into the study of expertise lies between realist and constructivist approaches. According to realist perspectives, expertise is a real and substantive skill that certain people possess. Constructivist approaches see expertise as attributional, as a qualification that experts enjoy based on it having been granted to them by others who have the prerogative to do so and which is subsequently socially recognized. Further distinctions can be derived from these two main perspectives, such as whether expertise is the property of individuals or groups, and whether it is primarily a form of theoretical or practical knowledge. In what follows, I will elaborate upon these aspects, but will at times simplify complex debates for the sake of clarity. In psychology, the realist model has been dominant, as expertise has been studied as a property certain people are endowed with, and the focus has been to determine how expertise is reached and to identify the differences between experts and nonexperts at the cognitive level. In this regard, Chi (2006) put forward the distinction between absolute and relative expertise. In the first case, expertise is conceptualized in a very narrow way, as the attribute of people who are extraordinarily gifted in a certain field, as very much informed by one's exceptional innate talent and abilities. Expertise is thus seen as a measure of performance, and the activities and behaviors of highly gifted people in a field are studied in order to understand how they perform, what makes them fail and succeed (Chi, 2006). In the second case, expertise is conceived more openly, as a continuum along which one can progress if certain contextual conditions are in place and if one is endowed with specific traits. According to Ericsson (2006), not only do experts know better, but they also know differently, as he emphasizes that expert knowledge is differently mentally organized, and they access and process information in other ways than people with less experience and knowledge. At the same time, Ericsson argues that experts also have specific self-monitoring habits, as they constantly reflect on their performances, they are aware of gaps in their knowledge and understandings and seek to improve based on these realizations. To a certain extent, this corresponds to the "structures of wanting" identified by Knorr Cetina (1997), and suggests that expertise is also based upon a certain disposition towards knowledge seen as "open and unfolding" (Edwards, 2010).

These debates about the realist or constructivist character of expertise have also been echoed in philosophy, where scholars have been particularly preoccupied by the practical or theoretical character of expertise. In so doing, they have built upon the distinction put forward by Ryle (1946) between knowing how and knowing that. Thus, in the one camp are supporters of the "fluency model", scholars who have chosen to highlight the embodied aspect of expertise, arguing that people with great ability in a field often act intuitively in reaction to a specific situation and environment, frequently bending or circumventing existing rules. Particularly important here is the five-stage model of expertise developed by Dreyfus and Dreyfus (1986), through which one's cognitive and affective trajectory from novice to expert can be traced. Building upon phenomenological insights, Dreyfus and Dreyfus (1986) argue that as one becomes more knowledgeable about a topic, one's relation to the world is transformed, including one's attitude and approach towards the field one is becoming an expert in. While at the beginning certain practices may still feel alien, and one may therefore feel scared and overwhelmed, as an expert one becomes fully immersed in one's practices, one experiences joy, euphoria, and deep commitment, and one can hardly distinguish between oneself and these practices. Scholars embracing the views of Dreyfus and Dreyfus (1986) argue that the knowledge of experts is tacit, as they often know more than they can articulate (Young & Muller, 2014). They thus share the interest on the performative aspect of expertise described above in relation to psychology. In the other camp are supporters of the Cartesian model, who highlight the theoretical knowledge of experts, as they argue that the knowledge of how to perform something is ultimately the knowledge of a fact (Stanley, 2011). One knows *how* to do something by virtue of knowing *that* something can be done in a particular way. Nevertheless, knowledge of a fact in their understanding is not "by its nature inherently contemplative, (…) [but] a state implicated directly in action" (Stanley, 2011: vii).

While the philosophers mentioned above have embraced a realist view of expertise, others have sought to combine realist and constructivist perspectives, albeit in different ways. For instance, Selinger and Crease (2009) have engaged directly with the five-stage model of expertise of Dreyfus and Dreyfus (1986) and have argued for the need to extend it by taking into account the role of personal, social, and cultural elements in shaping one's becoming an expert as well as one's behavior as such. More recently, Quast (2018) has promoted a "balanced account of expertise", arguing that "[h]aving expertise should not be reduced to the expert's functional dimension (…) or to the possession of ordinary dispositions to do [something] (…) expertise needs a more balanced understanding comprising serviceable dispositions and manifestations, on the one hand, and a corresponding service function on the other" (Quast, 2018: 412). Not only does Quast combine an ascriptive and realist perspective of expertise, but he also believes expertise has important normative dimensions, as experts not only need to make their expertise manifest in front of others, but they have to behave "correspondingly" in so doing. By this Quast means that experts also have a moral obligation to behave responsibly and be willing to account for their expertise, when called upon it by their audiences. This allows Quast to make an important distinction between personal competences and expertise, since the latter, being in his view partially the result of social ascriptions, can be lost relatively easier compared to the former. While there are important differences among philosophers regarding the realist or social character of expertise, they do share a focus upon individuals as the main locus on expertise.

In sociology, expertise has initially been studied from the perspective of the sociology of professions, with early studies seeking to understand what accounted for the differences between occupations and professions (Kotzee, 2014). Unlike in psychology and philosophy, the focus has therefore been mainly on expertise as a property of groups, developed through various processes of acculturation. Initially, a realist view of expertise seems to have dominated sociological studies, with various authors showing the differences between professions and occupations to be substantial and even providing various lists of characteristics for each of them (Evetts et al, 2006). In time, the constructivist approach to expertise has come to dominate (Koppl, 2010), and these authors have been subsequently criticized for helping maintain the authority of influential professions, such as medicine and law (Saks, 2012). Such critique is in line with (neo)Marxist perspectives which conceive of expertise as a social construction, as a means through which influential groups retain a monopoly over certain services (Foucault, 1972/2010), with professional training, standards, and evaluations seen as mechanisms through which outsiders of these groups are denied access (Susskind & Susskind, 2015; Illich, 1977). Building upon such insights, feminist and postcolonial scholars have denounced the close relation between knowledge, authority and power, and have shown the tenuous links between expertise, ethnicity, and gender, among others. From this perspective, rather than something real, based upon substantial ability in a given field, expertise is seen as an attribute bestowed upon certain members of society by specific institutions, but which has real and important consequences in terms of the distribution of power and privileges.

The debate regarding the contribution of STS scholars to the charges currently brought against expertise in "post-truth" discussions is still ongoing (Radder, 2018; Fuller, 2017; Sismondo, 2017; Collins et al, 2017; Lynch, 2017), but there is no doubt that they have been important proponents and advocates of the constructivist view on expertise. For instance, influential studies in the field (and in the sociology of scientific knowledge) have revealed how political and social considerations shape the production of scientific knowledge (Bijker, 1995; Shapin & Schaffer, 1985; Bloor, 1976; Barnes, 1974). In STS, currently, three main approaches can be distinguished in the study of expertise. The first highlights the substantial character of expertise and challenges the idea that public engagement means that all views are equal, represented by Collins and Evans (2007; 2002). A second conceives of expertise in terms of its institutional embedding, put forward by Jasanoff (2004). The third understands expertise as a property of discrete networks, which Eyal and colleagues developed in their study on autism (Eyal, 2013; Eyal & Hart, 2010; Eyal et al, 2010).

Seeking to determine the bases upon which members of different communities could be involved in decision-making processes at various levels based on the type of knowledge they were endowed with, Collins and Evans (2007) put forward the Periodic Table of Expertise. In their view, expertise is characterized by three dimensions: esotericity, or the degree to which expertise is confined to a particular group; the tacit knowledge required for it; and the changes in expert performance, which trace a novice's trajectory as s/he becomes a member of the expert group. For the topic of this dissertation, I have found it particularly useful to engage with Collins and Evans' insights, as on the one hand they have tried to open up the concept of expertise by acknowledging that people without official accreditations could also be experts in a given field, while on the other they have sought to ensure that expertise continues to designate something "real" (Collins et al, 2006:40). Particularly useful has been the distinction between what they call "contributory" and "interactional expertise", which Collins and Evans consider specialist forms of expertise requiring specialist tacit knowledge. While they conceptualize contributory expertise as the ability to contribute productively to a field, interactional expertise refers to the ability to become fluent in the language of practice of a given domain, thereby being able to engage in substantial discussions about relevant matters with contributory experts in that field (I discuss at length this form of expertise in chapter 4). Thus, Collins and Evans' conceptualization focuses on expertise as a matter of one's knowledge and competence. Importantly, Collins and Evans also acknowledge the heterogeneity of any given field in which one may hold expertise, which draws our attention to the fact that some people may have more expertise in a certain area of the field than in others.

While with this approach Collins and Evans fight relativism, it neglects the strong relational undertones of expertise, as it is acquired, maintained, and displayed in complex and often long-lasting exchanges with people with different levels of knowledge of that field and with different stakes in it. While I have found it productive to engage with Collins and Evans' understanding of expertise and to apply their typology of expertise in my analysis, the criticism their conceptualization has received is noteworthy. Jasanoff (2004), for example, who views expertise as embedded in practice, that is, as enacted in specific institutional settings, has reproached Collins and Evans for not having sufficiently taken into account the role of national and institutional cultures in shaping the development and content of expertise and the relations between experts and society at large. Jasanoff draws attention to the power institutions have to define what expertise is, thus emphasizing that socio-political elements play an important role in determining what counts as authoritative knowledge, and in ensuring the obduracy of such understandings (Jasanoff, 2004), be they more or less well-founded. They play an important role, as they ascribe authority and credibility, indicating who the public should trust and defer to in specific matters. Thus, according to Jasanoff (2003:393), "expertise is not merely something that is in the heads and hands of skilled persons, constituted through their deep familiarity with the problem in question, but rather (…) it is something acquired, and deployed, within particular historical, political, and cultural contexts."

These insights have guided my analysis, as I have made sense of the various enactments of expertise about bipolar disorder encountered on different types of online platforms by considering the scientific and social trajectory bipolar disorder has followed in the U.S. and France. They have also helped me better understand how different civic cultures in the U.S. and France, and different relations between medical professionals and people diagnosed, shape the ways in which official bodies use the internet (chapter 2), but also affect how people diagnosed seek to enact expertise online and why they do so (chapters 3 and 5). In chapter 2 these insights sharpen the critical perspective on the choices made by two official bodies to provide knowledge about bipolar disorder, and highlight how the use of the internet, a relatively new medium, can challenge established institutional approaches. The analysis focuses thus on the tasks different stakeholders manage to fulfill through their online contributions, on their social consequences, but also on prerogatives, jurisdiction, and authority.

Whereas Jasanoff conceives of expertise as grounded in institutions, Eyal has put forward an understanding of expertise as "a network linking together agents, devices, concepts, and institutional and spatial arrangements" (Eyal, 2013: 863). Building upon insights developed by Foucault (1972/2010) and Rose (1992), Eyal finds it important to distinguish between expertise and experts, arguing that the study of each requires different methods and casts light upon different aspects. In this understanding, expertise is not the attribute of any one individual, but it is distributed, coming into being through exchanges between "agents" endowed with different abilities and insights yet committed to solving a common issue through similar methods. Eyal developed this theory studying how the parents of autistic children challenged the psychiatric establishment and succeeded in putting forward a different understanding of this condition and in popularizing a new therapeutic approach. These transformations were set into motion, in Eyal's view, by a checklist that an army psychiatrist, book author and parent of an autistic child, Bernard Rimland, provided on the back of his book for the parents of autistic children to fill in and send back to him. Thus, the checklist represented an innovative model of knowledge exchange around which the network was organized, a means which allowed new stakeholders to contribute actively to the production of knowledge about autism. His distinction between experts and expertise allows Eyal to conclude that while psychiatrists may have lost in this way some of their territory, psychiatric expertise was in fact expanded in that it became part of a greater network, consisting of more domains and institutions and touching upon broader areas of life. Expertise as a network implies a variable level of flexibility, as it may be more or less easily rewired depending on the different stakeholder's resources, skills, and creativity, on the credibility they enjoy, and on the necessity to develop new goals.

This conceptualization of expertise is therefore applicable for the study of expertise about bipolar disorder online, as it allows to investigate how the internet supports new ways of knowledge production and exchange, and whose involvement is facilitated or rendered more difficult. Another advantage of this approach is that it may provide a way to bring together the realist and constructivist perspectives on expertise, since "[f]rom a network point of view, attributional struggles …. are about much more than the mere assignment of a label. They are about rearranging relations and rechanneling flows within a network of expertise." (Eyal, 2010:10) Eyal's point is that efforts to "rewire" a given network of expertise do not merely lead to a new group being acknowledged as "the experts" while the previous authority figures recede into the background. Instead, as different stakeholders stake their claims to expertise and as new tools, standards, and institutions join or are brought into the network, expertise itself is transformed, as the configuration of people and techniques through which it is enacted becomes different and as it comes to serve additional or new goals than was previously the case.

This resonates with developments in the conceptualization of expertise put forward recently by scholars working in different fields in response to the highly complex, dynamic and interconnected world we live in. Important here are the insights provided by Edwards (2010), working in the field of professional learning, in reaction to the realization that people with expertise in a given field are increasingly required to work outside the boundaries of their particular institutions, to enact their expertise in collaboration with specialists from different fields, with different training, methodologies and perspectives on the issues at hand. She argues that these realities have led to a "relational turn in expertise" (2010), as they require "an expertise which includes recognising and responding to the standpoints of others and is in addition to the specialist knowledge at the core of each distinct professional practice." (Edwards, 2010:2) Thus, unlike Kotzee (2014) who suggests distinguishing between forms of expertise depending on the level of social skills required, Edwards seems to believe that such skills have now become necessary at a more general level. While it is indebted to Collins and Evans' notion of interactional expertise, this perspective has the merit of seeking to move towards a more collective and dynamic understanding of expertise. These insights have been particularly helpful for this dissertation, as they have challenged me to consider how expertise could develop as an attribute of many rather than that of an individual, on online platforms where exchanges take place between frequently changing contributors, with different levels of online experience and differing interactional skills.

Building upon the relational aspect of expertise in a different way, Kotzee and Smit (2017), philosophers of science, tried to reconcile realist and constructivist views by putting forward a new conceptualization. Their starting point is the realization that both perspectives conceive of expertise as relational: in the first case, expertise is seen as consisting of the relationship between an individual and an ability; in the second, it consists of the relationship between an individual and others who acknowledge him/her as an expert in a given domain. Their solution relies on combining these elements to define expertise as one's "ability and/or level of knowledge…that significantly surpasses [that of others]" (Kotzee & Smit, 2017:647). Another merit the authors see in this conceptualization is that expertise is a matter of degree, which is in line with Ryle's views that ascriptions of intelligent actions are always uttered by invoking different degrees (Winch, 2014). Given the highly specialized world in which we live, knowing whose opinion to ask for and whose advice to trust on a specific issue is highly necessary, and expertise thus understood fulfills an important public function. Nevertheless, Kotzee and Smit fail to consider a third type of relationship, namely that which people with expertise in a field develop with others who hold expertise in a different field. Thus, while I have retained their emphasis on the link between expertise, trust and legitimacy in chapter 4, I have done so while working with Collins and Evans' concept of interactional expertise for reasons which are further clarified there.

A more recent and relevant contribution to the study of expertise comes from education and communication studies, where Engeström (2018) has argued in favor of the need to transition to a "collaborative and transformative expertise". Expertise derives then from common activities undertaken by different types of practitioners, who are flexible, open to new knowledge and capable of dealing with rapidly changing environments. Particularly relevant for this study is Engeström's (2018:1) argument that "[c]ollaborative and transformative medical expertise is continuous negotiation and hybridization of the insights of medical professionals and their patients. Without patients' insights, accounts, and actions, medical expertise would at best be merely top-down engineering." Rather than approaching expertise as an outstanding performance, Engeström studies it "as everyday work" by focusing on mundane situations when disturbances, breakdowns and/or rapid transformations interrupt daily routine. What is particularly interesting about his approach is that he takes a collective activity as a unit of analysis for expertise and considers it not only a matter of internalizing authoritative knowledge, but also as conducive to new ways to produce and manifest knowledge.

1.2 A new approach to expertise

While reflecting on the perspectives on expertise described above and engaging in the analysis of the materials presented in the following chapters of this dissertation, I realized that there was still room to contribute to a further refinement of this concept. I therefore developed a working definition of expertise, where I sought to integrate the elements that I found most important in the literature review I conducted with the insights I acquired from the analysis of online interactions. In so doing, I aimed not only to contribute to the further clarification of this concept, but also to develop a definition that could do justice to the dynamic and complex environment in which expertise is nowadays enacted. I define expertise as a practical achievement, realized though coordination and affective labor among stakeholders who occupy multiple and shifting positions across a complex ecosystem. Through this definition I position myself among scholars who take a constructivist as well as practice-oriented approach to expertise.

This definition is vastly indebted to Mol's (2002) concept of enactment, as the articulation and making manifest of substantial knowledge and abilities through complex entanglements of people and tools, are essential elements also in my understanding of expertise. Thus, the main difference between her perspective and the one I develop here may be seen as a shift in focus that may be dictated by the societal changes and practical transformations that have taken place in recent years. Mol put forward the concept of enactment because it allowed her to make clear that the distinction between human subjects and natural objects is blurred: "like (human) subjects, (natural) objects are framed as part of events that occur and plays that are staged. If an object is real this is because it is part of a practice. It is a reality *enacted*." (Mol, 2002:44, emphasis in the original) I share with Mol the concern to foreground the multiplicity of the object resulting from such practices, but I add to her perspective the emphasis on the numerous, fragmented, and dynamic identities of the actors involved, to use her terminology. These were not sufficiently considered, since her account focused mainly on the professional identity of the medical professionals studied, although some intimations thereof can be identified in her discussion of the life of "patients" outside the medical setting.

Enactments thus grant people and objects “fragile identities” (Mol, 2002), which may shift from the one site to the other.

I also combine Mol’s perspective with the more recent insights developed by Engeström (2018), in particular his emphasis on the collective, dynamic, and adaptable character of expertise in current times. According to Engeström (2018), expertise requires both vertical and horizontal types of movement, as knowledge in a given area needs not only to be deepened, but has to be enriched with knowledge from other, related areas. By combining this perspective on the dynamic character of expertise with Jasanoff’s (2004) call to pay attention to the cultural and institutional elements that shape it and with Quast’s (2018) focus on its deontic dimension, I was prompted to understand expertise as an achievement across a complex ecosystem. This view prompts the analysts to look beyond the practices they may be observing, to broaden their focus to include perspectives on the rights and obligations of the different stakeholders involved, on the prevailing cultural norms and expectations about their activities. Thus, how expertise is enacted constitutes both an illustration of and a reaction to specific legal, political, and educational provisions. For instance, new regulations about the acceptability of certain online practices and the use of online data may enable and deter people diagnosed with bipolar disorder to share their insights and seek to engage in epistemic practices using digital technologies.

Edwards’ (2010) views on relational expertise have highlighted the necessity for different types of professionals or stakeholders to work together in order to achieve a common goal, but Engeström (2018) sets the threshold somewhat lower by foregrounding coordination rather than agreement. This means that the stakeholders involved need not undergo a substantial transformation and come to share the same understanding of the various concepts, processes, and tools involved, nor do they have to use the same standards. What is important is that they agree to suspend their differences in order to achieve a common goal (a minimal form of agreement) under conditions of uncertainty and, often, within a limited time-frame. Thus, one of the advantages of “coordination” in relation to expertise is that it does not solely focus on the epistemic differences between individuals in regard to a specific topic or domain, that, for instance, Kotzee and Smit’s (2017) conceptualization highlights. But it foregrounds, instead, the development of more similar and equal (temporary) relations, thereby shifting the focus from people who have and do not have substantial abilities and knowledge in a field to the interactions between people who may be equally endowed, but in other domains, and who may have to work together to solve complex problems.

From psychological and philosophical perspectives on expertise, I learned about the importance of affective reactions in relation to the development of expertise (Selinger

& Crease, 2009; Dreyfus & Dreyfus, 1986), as highly competent people not only come to know things differently, but also feel differently about them. While these perspectives merely dealt with the affective responses an individual may have in relation to the practices at which s/he was (becoming) an expert, the online interactions I studied made me aware of the numerous emotions that arise and need to be managed when different people interact and share insights. Such emotions become all the more complex when different stakeholders come together, as was often highlighted in the data I collected where people diagnosed with bipolar disorder directly engaged with carers and medical professionals. Even interactions among people diagnosed could be short or longer-lasting, superficial or more substantial, depending on the emotions that dominated such encounters. That is why I have chosen to foreground affective labor in the definition of expertise I put forward, as it allows me to highlight both the importance of emotions in relation to a concept which is more often linked with intellectual and mental processes, as well as the affective work that people need to do in order to coordinate with other people and things. For instance, to enact lay expertise online, some people diagnosed had to overcome their fright or reservations regarding computers and the internet, they had to try to make themselves likeable or intriguing enough for others to interact with them, and they had to care for others, to respect their views and experiences and to help them develop more positive emotions.

From feminist theories, I have retained the focus on multiple standpoints (Harding, 2004), on the different meanings a certain issue can acquire depending on the perspective of those who look upon it, on the identity and position they occupy within a certain social order. While Richmond (2017) has suggested to approach expertise by considering the mediation work individuals or groups at the periphery are forced to undertake in order to (effectively) communicate with those at the center, I have found particularly useful her discussion of Lugones' concept of "mobile positioning". Thus, by paying attention to the multiple identities one inhabits, one may find ways to escape, obfuscate, resist or transform the norms and regulations of the communities one is part of, one may develop a more critical perspective on them. This has helped me consider the ways in which one and the same stakeholder may occupy different positions within the ecosystem where expertise is constituted, and to realize that these different positionings are managed, but also "stirred" in this process. For instance, in the field of mental health, numerous researchers and medical professionals are also patients or carers and fulfill executive functions whereby they contribute to the decision-making regarding the allocation of research funds.

In this dissertation, the online expert mediators discussed in chapter 4 position themselves as individuals diagnosed with bipolar disorder, experts by experience, representatives of people diagnosed with bipolar disorder, patients, advisors, successful entrepreneurs. It is their successful orchestration of these multiple identities and their ability to shift the focus from the one to the other, depending on the character of their interactions and of their goals, that have enabled them to become highly influential. Yet, this perspective remains valid also in regard to regular online contributors, as chapters 3 and 5 will show that people diagnosed with bipolar disorder shift between the positions of lay experts, knowledge producers, information seekers, patients, and concerned friends in their online interactions. Apart from its empirical grounding, this approach to expertise has also a strong normative undertone, as I believe the content and status of expertise would generally profit if the stakeholders involved would be helped to acknowledge and reflect upon the multiple social identities they inhabit and the inherent sources of bias, when they engage in seemingly well-delimited sets of practices.

As already indicated by the main research question and briefly explained above, I have decided to use the concept of enactment developed by Mol (2002) to study expertise about bipolar disorder. Using this concept means that I side with constructivist approaches to expertise, but it also allows me to move beyond them in a way which I believe is more in line with a study of online practices. This is the case because enactment foregrounds processes, materialities, events, and in so doing it does not allow even for the temporary stability most constructivist approaches imply. This concept is particularly useful in view of the approach to expertise I put forward, since it allows me to focus on the coordination work that is required for expertise to come into being and to retain a given consistency, while remaining a process. This allows me to foreground the impact of the internet and its multifaceted character on the practices that I study, as I can approach expertise about bipolar disorder as distributed across different online platforms, and shaped by the different technologies available on them. The following chapters in this dissertation will show some of the ways in which expertise can be enacted depending on the different stakeholders involved and on the ways in which they engage with the online affordances of different online platforms. Before moving on to that, however, there are still a few elements which need to be introduced, namely bipolar disorder, the role of the internet in the study of expertise about this condition, and how mental healthcare is organized in the U.S. and France.

1.3 Bipolar disorder

Mental health conditions are the result of complex interactions between individuals with a certain biological make-up and their physical and social environment. Symptoms of what would later be known as bipolar disorder were first presented in the 1850s to the *Académie de Medicine* in Paris by Baillarger, who called it *"folie à double forme"* (dual form insanity), and Falret, who referred to it as *"folie circulaire"* (circular insanity) (Angst & Sellaro, 2000). Both scientists agreed that this condition had a terrible prognosis, and Falret postulated that it had a strong genetic basis. In the 1900s, Kraepelin was also pessimistic about the outcome of patients exhibiting such symptoms, but observed that they also experienced intervals when no "abnormal" functioning could be detected. He used the term "manic-depressive psychosis" to distinguish this mood condition from "precocious madness", which later became known as schizophrenia (Angst & Marneros, 2001). The term "manic-depressive illness" was coined in the 1950s, which roughly coincides with the period when lithium salts started their successful, still ongoing career as treatment for this condition, following a discovery by Australian psychiatrist John Cade (Healy, 2008). In the 1980s the name was replaced by "bipolar disorder", thought to be less stigmatizing, but this change continues to be debated, as many medical professionals and people diagnosed consider the former denomination to convey the character of this condition more appropriately.

Currently the presumed causes of bipolar disorder represent a mixture of neurologic, genetic and environmental factors, and this condition is managed through a combination of medication, therapy and counseling. Because of the similarity in symptoms with major depression, bipolar disorder remains difficult to diagnose correctly, and often many years (5-12) and numerous encounters with various mental health professionals are necessary. In the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013), this condition is coded as bipolar single manic, bipolar manic, bipolar depressed, bipolar mixed, each category containing several subtypes. The International Classification of Disease and Health Related Problems (ICD-10, 2010) groups conditions based on their relatedness to each other, so different forms of bipolar disorder are spread under the headings of various types of mental health conditions. An important distinction both in regard to diagnostic difficulties but also in relation to treatment lies between the types Bipolar I Disorder and Bipolar II Disorder. These two types differ mainly in the severity of the manic episodes experienced. Whereas Bipolar I Disorder involves severe manic episodes, lasting for several days and at times requiring hospitalization, those diagnosed with Bipolar II Disorder experience hypomanic states rather than full-blown manic episodes (Grande et al, 2016). Even though the enormous increase in people diagnosed is often ascribed to improved diagnostic tools, it may also be due to a positive re-evaluation of this condition. Martin (2009), for example, argues this is the result of a close connection between the values of capitalism and some of the traits associated with manic episodes: creativity, passion, dedication, intense activity. In contrast, others have explained the growing number of people diagnosed with bipolar disorder by arguing that the values of capitalism lead to stress, anxiety, and depression (Hidaka, 2012), while yet others have linked this increase to tendencies to medicalize social issues (Esposito & Perez, 2014) and to pathologize variations in human experiences (Horwitz and Wakefield, 2007; Scott, 2006).

Bipolar disorder has also been affected by recent developments in personalized and precision medicine, which provide visions of medical interventions tailored to the specific needs and circumstances of individuals. Doubts about the scientific character of expertise about mental health have led professionals to embrace perspectives and procedures which have deeply anchored this condition in biology, in processes which could be identified, measured, and acted upon through targeted approaches. As such, in the aftermath of the Human Genome Project (1990-2003), numerous research projects (Cruceanu et al, 2009; Alda et al, 2005; MacQueen et al, 2001) have been undertaken, which have sought to identity the phenotypes and genetic markers underlying bipolar disorder, the predictive factors of response among different (sub)groups of people diagnosed, and new drug targets. At present, however, bipolar disorder seems to be characterized by too great genetic and phenotypic heterogeneity for these insights to be very helpful. Furthermore, since treatment response in many of these studies was measured with different instruments, the translation of these new insights into clinical practice is likely to take some time and to require collaboration and intense efforts among a very broad range of professionals, including not only medical specialists but also engineers and computer scientists.

As a chronic, life-long condition, bipolar disorder affects all aspects of life for those diagnosed with it. In studying the online enactment of expertise about bipolar disorder, I focus both on aspects regarding its treatment, and on the lived experience thereof. These aspects are crucial as they illuminate the main prerogatives and issues of contention that have marked the debates regarding medical/professional and personal authority in healthcare. By adopting this focus, strategies designed from above in order to shape the behaviors of people diagnosed are combined with the various coping mechanisms that those diagnosed develop themselves. By bringing the personal, experiential aspect of treatment into dialogue with its more distant, medical facets, it is possible to better understand the various approaches through which different ways of knowing are combined in the enactment of expertise about bipolar disorder.

1.4 Studying expertise about bipolar disorder online

While the internet is intensively used these days for health-related purposes, it continues to divide opinions about the ways in which it shapes (mental) healthcare, and about the benefits and disadvantages of its use for different stakeholders. For instance, while initially wary of this medium, over the last decades governmental officials have increasingly promoted it. This has been the case because they hope the internet will help them solve what many consider to be an impending crisis in mental healthcare, as the number of people diagnosed has been increasing, while the budget allocated for this sector has diminished. In the scenarios embraced by these stakeholders, the internet is supposed to facilitate the provision of cost-efficient mental healthcare, by allowing people diagnosed to become more knowledgeable about mental health and by enabling those living in remote areas to contact medical professionals and to engage in online therapies (see chapter 2 for a more detailed discussion). These tendencies have acquired renewed impetus with the move towards personalized and precision medicine and with the hopes generated by Big Data analytics. These have changed the ways in which health and disease are conceptualized and have emphasized the need for (self) surveillance and for collecting highly diverse types of data both from people diagnosed and from those not (yet) diagnosed (Prainsack, 2018; Hogle, 2016). In this context, active forms of patienthood have been encouraged not only by public stakeholders, but also by commercial actors, which have started to become more involved in healthcare (Sharon, 2016). At the same time, the internet has also been enthusiastically embraced by many people diagnosed and their families, who have hoped that they would thus learn to better manage their condition and to steer research processes in ways they found relevant. Digital technologies have facilitated communication and collaboration between different stakeholders, and allowed people diagnosed to track various physical and emotional states, to enroll in online studies, and to share their personal experiences online.

There have also been a growing number of critics (Lupton, 2018; Neff, 2013; Brown & Baker, 2012), who have interpreted such forms of (pre)patient participation as strategies through which governments place greater responsibilities upon citizens in a context where social provisions are cut and where a market logic is increasingly used to guide the provision of mental healthcare. At the same time, scholars have also criticized users' engagement with digital technologies as a form of free labor (Mitchell & Waldby, 2010; Waldby & Cooper, 2008; Terranova, 2000), where people are encouraged to constantly monitor themselves in pervasive and invasive ways, but are required to give up ownership over their data and any claims over potential profits that can be made from them. Others have also worried about the different ways in which such data may be used and how they may affect the individual users of such technologies but also the prescription practices of medical professionals. Such concerns are particularly well-founded in the U.S., where Section 2713 of the Affordable Care Act stipulates the establishment of "guidelines to permit a health insurance plan to use value-based insurance design" (National Conference of State Legislatures, 2018). Thus, while some believe the internet can be harnessed to help solve numerous problems in mental healthcare, others worry about the effects of online practices, about the ways in which people diagnosed understand themselves and their condition, and about the ways in which the internet can shape relations between them and medical professionals. This dissertation contributes towards a better understanding of these aspects and it does so by engaging more specifically with two recurrent ideas about the internet's potential, namely its ability to democratize and to help transmit local and cultural norms.

The accessibility of the internet since the early 1990s for people in the Western world meant that many scholars initially believed that this medium would have a democratizing effect (Koch & Schockman, 1998; Rheingold, 1993). This was particularly the case in medicine and mental healthcare, where for a long time, medical professionals were very successful in defining the insights and practices that constituted expert knowledge and in determining to whom and under what conditions it could be made available (Foucault, 1972/2010; Turner, 1995). By allowing people diagnosed to access medical information previously reserved strictly for medical professionals, by enabling them to learn about alternative or exotic approaches to mental health, and by facilitating their contributions to epistemic practices, in the early days of the internet some medical sociologists and media scholars thought that it would contribute to the democratization of relations between medical professionals and their patients (Hardey, 1999; Poster, 1999). In the meantime, more nuanced studies (Wyatt et al, 2016; Nettleton & Burrows, 2003) have been published, which have problematized the internet's democratizing potential, highlighting the multifaceted character of this medium, and the heterogeneity of people who search for and contribute to health-related information online. Scholars have also argued that the internet leads to new forms of inequality engendered by various algorithms, including those of search engines, which determine the visibility of online platforms (Bishop, 2018; Pasquinelli, 2009; Hargittai, 2007). The resources available to people are thus not equally distributed, as online communication skills, familiarity with various technologies as well as the size and impact of on- and offline (professional) networks can differ considerably. Furthermore, despite their increasing popularity, interactive platforms have not replaced non-interactive websites, but co-exist with them.

The choice of an interactive or non-interactive platform is determined not only by the goals and preferences of users, but also by their resources and position. Thus, important institutions with a generous budget can invest in their platform, but need to shape the information provided in view of their values. In contrast, smaller stakeholders may need to settle for a platform they can afford or select a design that will attract many visitors, and attune their message to their (prospective) sponsors' preferences. These choices may affect a platform's index score with a search engine, which can have profound consequences, as studies about people's online search behavior indicate that users often do not look beyond the first few results pages (Höchstötter & Lewandowski, 2009; Bar-Ilanet al, 2006). Thus, the type of platform selected and its design significantly influence how information is provided, and the types of knowledge made available.

Initial studies on users' online behaviors were built on the assumption of a pre-existing difference between online and offline environments, with the internet seen as a realm apart, where people could try out different identities irrespective of their actual life circumstances and of their location. Over time, researchers have become interested in the interactions between online behaviors and offline practices and their effects. In the early days of the internet 1.0, some scholars saw this medium as an instrument of globalization, and believed that it would help bring about cultural homogeneity through the seamless flow of information among people from all corners of the world, and through the subsequent effacement of local practices in favor of cosmopolitan approaches (Featherstone et al, 1995). After 2000, however, a growing number of anthropologists and media scholars have drawn attention to the specific contexts in which online contributions are made, and have argued that social and cultural norms importantly shape people's online behaviors (Ardichvili et al, 2006; Fox et al, 2005; Miller & Slater, 2000). Yet little is currently known about the ways in which local and cultural markers shape online exchanges about mental health, and this is one of the aspects that this study addresses by comparing how expertise about bipolar disorder is enacted on American and French platforms. In so doing, it focuses on the ways in which online contributors from these countries use different online platforms and the online affordances available on them to determine how local perspectives shape people's orientations towards bipolar disorder online.

1.5 Mental healthcare in the U.S. and France

In conducting cross-national research, I build upon findings provided by scholars in media studies, STS, and medical sociology. As mentioned above, the former showed that the internet is situated and used in culturally specific ways (Orgad, 2005; Miller & Slater, 2000). I also use the insights provided by sociologists of science, who have emphasized that expertise is shaped by the social and cultural context of its performance, discussed above. Whereas DSM-5 and ICD-10 largely determine how mental conditions are diagnosed around the world, according to medical anthropologists there remain significant cultural differences in their conceptualization and management.

1.5.1 Mental healthcare in France

At the beginning of the 21st century, the French healthcare system was voted the best out of 191 nations (WHO, 2000), but such an extraordinary ranking came at a very high cost. In 2013, for instance, roughly 10.9 % of the country's GDP was allocated to the health sector (OECD Health Statistics 2015). In the field of mental healthcare more specifically, the French government has been confronted with multiple challenges, leading researchers to note at various moments in time that French psychiatry was in crisis (Coffin, 2009; Pignarre, 2006; Castel, 1981). In 2008 mental conditions represented about 32% of the country's overall disease burden (WHO, 2008) and their incidence has been steadily increasing (OECD, 2016), thereby placing tremendous financial pressure on the mental healthcare system. In France most citizens are insured and have free access to mental healthcare in the public sector. At the same time, persistent challenges regarding the distribution and quality of care have demanded the attention of the authorities. Since the 1960s public mental healthcare in France has been organized in sectors, with each sector providing care to roughly 70,000 adult inhabitants (Verdoux, 2003; Verdoux & Tignol, 2003). Undertaken largely in response to calls for reform made by the antipsychiatry movement (Castel, 1981), the sector was designed as a means through which mental healthcare could be provided by a multidisciplinary team of professionals headed by a psychiatrist, who were familiar with the community, and who could guide and assist the patient's reintegration, thereby importantly ensuring continuity of care (Petitjean, 2009; Coldefy, 2007). Nevertheless, there remain significant differences between sectors regarding the resources they dispose of, the availability of outpatient clinics, and the number of mental hospitals (Coldefy et al, 2009; Coldefy, 2007; Verdoux, 2003; Provost & Bauer, 2001).

As the process of deinstitutionalization has occurred at a much slower rate in France than in other countries (Petitjean, 2009), most of the state's budget for mental health continues to be allocated to in-hospital forms of treatment (OECD, 2016; Petitjean, 2009), while outpatient alternatives are insufficient. Furthermore, since the psychoanalytical model remained the dominant approach to mental health until the 2000s, some claim that the French mental healthcare system is characterized by "underdevelopment in community psychiatry, accessibility of mental health professionals trained in cognitive-behavioral psychotherapy, and psychiatric research" (Verdoux, 2003:85). At the same time, there are great discrepancies regarding the distribution of medical professionals, with rural areas (Coldefy et al, 2007) or regions in Northern France (Petitjean, 2009; Verdoux, 2003) struggling due to a low number of specialists. The reforms undertaken thus far will most likely lead to greater inequalities, as the number of psychiatrists, currently among the highest in the world, is planned to decrease by 40%, reaching about 8,000 in 2020. This will importantly affect people diagnosed with bipolar disorder or in need of such a diagnosis, since in France the diagnosis, treatment, and evaluation of the patients' evolution are determined by psychiatrists, with general practitioners (GPs) functioning as first point of contact and subsequently as the ones who administer the treatment and are frequently in touch with the patients.

According to Swain (1988), the history of French psychiatry has been profoundly marked by its confrontation with a double temptation: the provision of therapeutic care and of social assistance. In regard to the latter, in the aftermath of the Second World

War, self-help and support groups in mental health started to develop. An important landmark in the development of support groups was the founding of the Croix Marine movement (*Fédération d'Aide à la Santé Mentale Croix Marine*). It was initiated by three psychiatrists —Pierre Doussinet, Alice Delaunay, and Elizabeth Jacob— in 1952, with the aim of providing protection and mutual psychological and social help to people diagnosed with mental conditions. While over the following two decades the provision of ambulatory care launched this way developed further, changes in French legislation in the 1970s regarding the status and prerogatives of social and medico-social institutions led to a strict separation between the provision of medical care and social action. Inspired by the 1968 events, a number of psychiatrists together with people diagnosed with mental conditions founded the *Groupe d'Information Asile* (GIA) in the early 1970s (Bernardet et al, 2002), to fight against repressive practices in psychiatry. The group has since developed a strong juridical orientation and claims to have played a major contribution in the 2010 decision of the Constitutional Court, by which all methods of involuntary commitment previewed under French law were declared anticonstitutional (Troisoeufs & Eyraud, 2015). In the 1980s, the first association of people diagnosed with mental conditions focusing on defending the rights of patients, *L'Association des Psychotiques Stabilisés Autonomes* (APSA), was founded with the support of psychiatrists. The first patient group with a specific focus on advocacy, *Advocacy France*, only came into being in the 1990s, drawing inspiration from advocacy groups in the U.S. (Laval, 2015). Nevertheless, most French self-help and support groups still focus primarily on the provision of support and education for people diagnosed and their families (Troisoeufs & Eyraud, 2015). As these examples illustrate, while throughout the 20th century, French psychiatrists sought to improve the provision of mental healthcare in a variety of ways, it was only towards the beginning of the 21st century that they started to engage in more meaningful collaborations with people diagnosed (Laval, 2015). This has had important consequences for the relevance and form of organization of self-help and support groups. Thus, even though in recent years their number has increased, most of them continue to function locally, they do not reach broad publics, and have little political influence.

1.5.2 Mental healthcare in the U.S.

The American mental healthcare system has also been confronted with important challenges over recent years (Boyle & Callahan, 1995). In 2002, the chair of the President's New Freedom Commission on Mental Health stated that "the system needs dramatic reform because it is incapable of efficiently delivering and financing effective treatments — such as medications, psychotherapies, and other services— that have taken decades to develop. Responsibility for these services is scattered among agencies, programs, and levels of government" (Hogan, in Grob, 2005:156f). Even though de-institutionalization occurred in the U.S. at a very high rate, few solutions were put in place to enable people diagnosed to receive the care they needed within the community (Estroff, 1985/2001), and not many people knew about them, even when such solutions existed (Grob, 2005). While in France the psychoanalytic model was dominant until recently, in the U.S. psychiatry has embraced the biomedical model since the early 1970s. Yet, not all people diagnosed with mental conditions have access to the same type of treatment (Hogan, 2003), as in the U.S., the quality of care very much depends on one's type of insurance as well as ethnicity (Kataoka et al, 2002). At the same time, it is also importantly influenced by the state in which one lives, in ways which echo somewhat the differences between the French sectors. Thus, in different states, mental healthcare services are reimbursed to varying degrees, and managed care controls limit access to costly services, while seeking to promote cheaper options more widely (Scheid, 2000). At the same time, the availability of community services differs, and there are still important discrepancies regarding the number and type of medical professionals available. For instance, while in New York, Massachusetts, and Vermont there are more than 15 psychiatrists per 100,000 people, in Texas and Idaho there are fewer than six (Simon, 2015). Furthermore, there appear to be over 4,000 areas across the U.S. with only one psychiatrist for 30,000 people (Simon, 2015). While in France the decrease in the number of psychiatrists has been planned by the national government, in the U.S. the demand for mental health professionals has increased. An important role in this regard has been played by the passage of the Affordable Care Act, which has enabled more people to have access to healthcare. Furthermore, the U.S. struggles with the impending reduction of psychiatrists, due to retirement — 59 % of psychiatrists in the U.S. are 55 or older — and an ongoing trend of diminished interest among medical students for this specialty (Simon, 2015; Neff et al, 1987).

Since the 1950s, the main paradigm in the U.S. for approaching and understanding mental conditions has shifted from a psychosocial model to an increasingly biomedical model, whereas community mental healthcare has followed a different trajectory, in time shifting its focus from helping people diagnosed to control their symptoms in order to avoid hospitalization to assisting them towards rehabilitation and recovery (Drake et al, 2003). Self-help groups have thrived as a consequence of this change in orientation, benefitting from support from various organizations, including official bodies. These developments have taken place in a context where calls made to reform mental health hospitals and turn them from places of confinement into spaces where care and assistance were provided led to different expectations being formulated regarding the responsibilities of medical professionals and people diagnosed, and to new types of professionals and more social actors becoming engaged in the provision of mental healthcare services (Norman, 2006). The 1980s inaugurated a period of proliferation and diversification for self-help and (mutual) support groups. Such developments took place in a context of growing realization that the availability and accessibility of community care provisions were insufficient due to the rapid pace of de-institutionalization, ensuing organizational loopholes and insufficient funding (Brown, 1988; Estroff, 1985/2001).

In the U.S. self-help and support groups have their origin in two different types of organizations. Thus, self-help groups are linked to the funding of Alcoholics Anonymous (AA) in 1935, from which self-help groups have borrowed important organizational as well as ideological elements. In 1948, the first Fountain House, a social club for people diagnosed with mental conditions, was founded in New York by We Are Not Alone, a group of ex-patients from the State Hospital. In the 1950s the Fountain House came under the leadership of a social worker, and broadened its focus to include, next to socialization, employment training, so that its members could gain and retain jobs (Dincin, 1975). This model has spread and thrived over the years, now counting clubhouses across the U.S., U.K., and Scandinavia. One of the first instances of support groups in the U.S. is Recovery, Inc., which was founded by the neuropsychiatrist Abraham Low in 1937 in Chicago, to care for people with mental conditions after their discharge from hospital. While soon thereafter Recovery, Inc. also turned into a self-help group, its success has been more modest compared to AA and other similar groups. Despite important differences, both in France and in the U.S., the development of self-help and support groups has taken place in a context marked by the processes of de-institutionalization and healthcare reform.

1.5.3 Relevant similarities and differences

To highlight the most relevant aspects for this study, the U.S. and France are among the countries experimenting with telemedicine in order to provide people in remote areas with medical care, and to reduce costs. However, there are notable differences between these countries regarding the diagnosis and management of mental conditions. In France, mental disorders are diagnosed based on ICD-10, and in the U.S. diagnosis is based on DSM-5. The systems differ in their theoretical orientation and in their medical approach, which affects the types of treatment offered and preferred, and the prescription and use of medicines (Gallini et al, 2013). In France de-institutionalization developed later and at a much slower pace than in the U.S. (Provost et al, 2001). Each approach conceives of mental conditions differently, which shapes how the personhood and autonomy of people diagnosed are understood. With the incidence of bipolar disorder about 4 %, the U.S. is the country with the highest number of people diagnosed in the world. In France, the rate is significantly lower, with 1.5-2 % of the population being diagnosed[1]. Interestingly, the results of the most recent French national survey suggest that bipolar disorder is starting to become a gendered condition here, as the statistics

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[1] The exact numbers may differ depending on the studies consulted, and on the forms of bipolar disorder included.

indicate that there are 1.6 times more women diagnosed than men, the difference concerning specifically bipolar disorder type II (Vaugrente, 2018). While the effects of advocacy movements have been less pronounced in France than in the U.S., stigma remains rampant in both countries. Comparing French and American contributions will therefore highlight the challenges inherent in transforming a mental health system, and whether such changes allow for a greater impact of American tools, practices and perspectives in France, bringing about, for instance, changes in the medications prescribed or in the diagnostic tools used. Since in France mental healthcare is mainly publicly funded, I expect the online experiences of French people diagnosed with bipolar disorder to be more similar than those among their American counterparts, living in a system characterized by greater diversity in healthcare provision, between states as well as insurance providers. A focus on the enactment of expertise about bipolar disorder in regard to treatment has therefore also allowed me to consider how the organization of national healthcare systems shapes online interactions.

While its globalizing effect has been frequently emphasized, the internet remains a carrier of local markers, and it is used in culturally specific ways (Josefsson, 2005). I have found a comparative approach useful because of the important interest and preoccupation manifested by both countries in regard to the use of the internet for healthcare practices. While initially cautious, over recent years French authorities have sought both to encourage as well as to regulate the (medical) use of the internet. Thus, France was the first country in the world to propose to its citizens the use of HONcode, an online certification tool for health-related websites (Silber, 2009), as a means to ensure that they have access to reliable and accurate medical information. While the quality of health information available online has been amply debated also in the U.S., here matters are further complicated by jurisdiction and authority struggles between federal institutions and the individual states. The overall availability of online healthcare services and information becomes highly problematic once the differences in legislation between individual states are taken into account. This dissertation studies the enactment of expertise about bipolar disorder on American and French platforms in order to understand how different stakeholders use the internet to produce knowledge and how their social and cultural background shapes their online contributions.

1.6 Methods and sources

Methodologically, this dissertation draws upon qualitative empirical material of two types: data collected from different online platforms on bipolar disorder and articles from medical journals. In chapter 4, the data used also include information acquired through an e-mail interview with Julie A. Fast, one of the bloggers studied, which took place across several e-mail exchanges in May 2017, as well as information from other online platforms that mention the two bloggers studied.

I conceive of online platforms as spaces which are socially created through interactions and practices between numerous stakeholders. At the same time, online content is importantly shaped by the online affordances available on different platforms, by rules of access and behavior, as well as by the tools and formats contributors can choose from. Taking up Franklin's (2001) reading of de Certeau in relation to online activities, I consider online contributions as activities integral to the everyday life of their authors, who shape the online spaces they are active on and are in turn shaped by them. The advent of Web 2.0 has heightened the profile of interactive platforms, which are characterized by a high media convergence (Herring, 2012), meaning that information is increasingly provided through a combination of text with other visual, audio, and video materials. Yet, such platforms exist in an environment that they share with non-interactive platforms, which are less dynamic, complex and open. Non-interactive platforms dedicated to mental health generally include websites belonging to influential institutions, be they governmental bodies, or patient organizations, which importantly shape the provision of treatment and care for people diagnosed with bipolar disorder. While the access to the information they provide is public, the contributors are selected by that particular institution, and are generally medical professionals. Interactive platforms include blogs and fora, and differ in terms of type of contributors and intended audience. While noting that not all such interactive platforms[2] are equally developed, Kordzadeh and Warren (2013) identified four major types: professional-to-professional; professional-to-consumer; consumer-to-consumer; and consumer-to-professional. Even though it is obviously useful, this typology is not sufficient, since it does not take into account that one may have multiple presences online. Medical professionals may address, for instance, the same or a different audience in their professional quality, as citizens, or even as people diagnosed, by contributing on different types of platforms. I therefore study both interactive and non-interactive platforms, since such a comparative approach contributes to a better understanding of the enactment of expertise in a context in which contributors travel across different online platforms and, in so doing, may significantly modify the shape and nature of their contributions.

Another reason for deciding to collect data from different types of online platforms is because they are endowed with different affordances, and require different levels of skills and resources by their users. While frequently used in STS, media and

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[2] The authors refer to these as "collaboration platforms". I prefer the term "interactive" because it allows one to bear in mind the differences in power and resources that different contributors to these platforms can draw upon.

communication studies as well as psychology, the concept of "affordances" has often been criticized. Critics have challenged this notion because of its ambiguous meaning, because it seemed to artificially distinguish between artifacts which afford and artifacts which do not, and because it did not appear to allow for complex relationships between users and artifacts (Evans et al, 2017; Nagy & Neff, 2015; Torenvliet, 2003). More recent conceptual contributions have, however, helped clarify the notion of "affordances" and render it even more useful as an analytical tool. In using it here, I take up the perspective developed by Davis and Chouinard (2016), according to whom affordances denote mechanisms which are conceptually relational and which place different opportunities and constraints both on users and artifacts. This means that when studying how expertise about bipolar disorder is enacted on different online platforms, I do not consider each platform and the functions embedded in its design equally accessible to all users. The online contributions of different users are therefore informed not only by the availability or absence of various functions, such as the ability to comment and to upload texts, graphs, images, and videos, but also by their own skills, preferences, and attitudes towards these technologies as well as by what they hope to achieve through their sharing practices. While certain users may avoid using specific functions even when available, others may be skillful and creative enough to circumvent certain rules. For instance, while on certain blogs and fora there is a word limit on one's comments, some contributors manage to bypass it by sharing their insights over a series of comments. Thus, how online affordances are used depends on the users' perception, dexterity, as well as on the affordances' cultural and institutional legitimacy (Davis & Chouinard, 2016).

In order to understand how the internet shapes the enactment of expertise about this condition, the aim was to collect and analyze data from different types of online platforms, authored by different stakeholders. In selecting the online platforms from which data were collected, I aimed to reproduce the behavior of average internet users and conducted queries using the index of the search engine Google as a relevance indicator. A list was thus made of the online platforms mentioned on the first 30 pages of results. This list was subsequently filtered to exclude online platforms in other languages than English and French, to eliminate multiple pointers to the same item and websites where the content was not focused on bipolar disorder or which were not free to access, but required registration or payment. Since language is not a reliable indicator, the domain of each platform was subsequently checked and only the online platforms were retained where American and French official institutions were mentioned. This was done to ensure that online data were collected from contributors in these two countries. More detailed information about the selection process is provided in the "methodology" section of each empirical chapter. The table below gives an overview of the online platforms from which data were collected and a short description of each of them is provided in Appendix A. An overview of the blog posts and forum threads used in each chapter is available in Appendix B. These platforms were selected because their visibility and popularity rendered them appropriate sites to study the ways in which different stakeholders come together online and enact expertise about bipolar disorder through their (inter)actions.

Table 1.1 List of selected platforms for data collection

PLATFORM NAME & COUNTRY	PLATFORM TYPE	PLATFORM MANAGEMENT
National Institute of Mental Health —U.S.	Non-interactive	Governmental agency
Bipolar Burble — U.S.	Blog	Person diagnosed
Bipolar Happens! — U.S.	Blog	Person diagnosed
Bp Hope — U.S.	Forum	People diagnosed
La Haute Autorité de Santé (HAS) —France	Non-interactive	Governmental agency
Doctissimo — France	Forum	People diagnosed; mediated by medical professionals
Le Forum des Bipotes — France	Forum	People diagnosed

Data were collected at different moments between June 2014 – September 2018. I adopted this approach because online contributors often change their mind about the online reactions they provide and amend them (multiple times) or remove them altogether at later moments. By collecting the data from the same platforms in different periods, I was able to identify instances when comments had been edited or removed by the people who had written them. I interpreted such practices as indications that the online contributors did not want them to be used or, at least, not in their original form. In the analysis, I have therefore only used the most recent version of the data collected, even if at times this meant removing comments and quotes previously used in the analysis.

In order to understand how expertise about bipolar disorder was enacted on these different online platforms, how meaning and culture were (re)produced online, I used qualitative methods which could provide "deep knowledge" of such dynamic and situated practices (Markham, 2016). The specific methods used in each chapter vary, but they include computer-mediated discourse analysis (chapter 3), thematic analysis (chapters 2, 4 and 5), and conversation analysis (chapter 5) adapted to online contexts. By using these methods, I was able to understand how different stakeholders engaged with online affordances, how they claimed particular identities for themselves, and how they sought to indicate that they were endowed with substantial knowledge on bipolar disorder.

The approval of the Ethical Review Committee Inner City (ERCIC) of Maastricht University was sought and obtained on April 6, 2016. It was not feasible to obtain informed consent from all the online contributors who posted information on the platforms from which I collected data. This was partly due to their sheer number and partly due to the fact that the contributions collected span roughly 10 years, a period in which many people who shared their insights may have stopped using these platforms or may have changed their usernames. Placing an announcement about this study on the platforms from which data were collected was considered, but was not done, as it was deemed that it would most likely not have amounted to more than a sign of good will on behalf of the researcher and would not have come close to the ideal of informed consent. The dynamic nature of interactions on blogs and fora, where contributions are often made in rapid succession, means that a contributor's post quickly stops been actual or visible for newcomers. Thus, placing an announcement would not have helped for contributions that had already been made and would most likely not have informed more than a few people after it was posted, depending on the level of interactivity on the platforms at the moment when the announcement would have been made. Instead, I decided not to engage in participant observation, but to use the data available on these platforms after a sufficient amount of time would have passed for contributors, who may have been unwell at the time when they wrote their posts or who may simply have changed their mind about it in the aftermath, to have the chance to edit or remove them. Since data were collected from platforms with a public character, this study meets current ethical guidelines for online research. For instance, according to the British Psychological Society (BPS, 2013:7), "where it is reasonable to argue that there is likely no perception and/or expectation of privacy (or where scientific/social value and/or research validity considerations are deemed to justify undisclosed observation), use of research data without gaining valid consent may be justifiable." A decision was also made against the anonymization of online contributors whose comments were used. Instead all quotes are provided verbatim and are accompanied by usernames. This decision was made in order to acknowledge the relevance and labor involved in these reactions and out of consideration for the fact that online contributors may have internalized these usernames as part of their identity (Varis, 2016). It was also based on the understanding that anonymity cannot be guaranteed, as usernames can be easily traced and retrieved based on quotes.

1.7 Ethical and methodological reflections

This dissertation focuses on the ways in which expertise about bipolar disorder is transformed by the use of online technologies, and the very process of studying this topic was shaped in significant ways by the fact that it is based on online data. Thus, not only the phenomenon studied here presented challenging aspects, but also the process of online data collection was marked by some difficulties. For instance, I was confronted with the uncertainty inherent in the absence of clear regulations and legal provisions regarding the use of online data for research purposes, with the complexity derived from conducting research by collecting online data from different countries and analyzing them in yet another, with the practical but also ethical difficulties of figuring out who the owners of such data are or who should be consulted about their use and when. Over the four-year period when this study was conducted, a growing number of interactive online platforms applied for and were granted copyright for the information provided online by regular users, who wanted to share their experiences and learn from others, without expecting any additional gains. This process of copyright acquisition was especially intensified prior to and in the immediate aftermath of the adoption of the General Data Protection Regulation (GDPR) within the European Union, which was enforced on May 25, 2018. Likewise, the number of platforms (in many different fields) specifying in their Terms of Use that researchers are not allowed to use the insights provided online by online contributors increased, even though the platforms remained publicly open, and did not require any registration or fee to access such information.

This is an aspect that has not yet received much attention in the literature, as some scholars interested in online research ethics have focused more on the obligations of researchers towards the people whose data they use (Markham & Buchanan, 2012). Others have problematized the practices through which big technology companies collect, use, and sell or re-use data from the users of their services and have warned about the limited usefulness of approaches such as informed consent and anonymization in this context (Barocas & Nissenbaum, 2014a). My experience, however, and, no doubt, that of many other scholars studying online practices is that online platform owners are turning into important gatekeepers in regard to the opportunities that researchers have to use the online data made available there and/or to place research announcements or engage directly with online users. Combined with the lack of clear international regulations (Edenberg & Jones, 2019), such gatekeeping practices have important consequences for online research, as they privatize access to study sites and data, rendering the possibility of conducting studies dependent on the considerations and preferences of people who may lack the necessary training to assess the merits, risks, and possible contributions a study can make. Moreover, the possibility of such negotiations itself may slowly become a luxury option for researchers, as it is more and more common for one's study requests to be ignored or rejected by a call center employee without any further explanation. Such practices contribute to new inequalities in (mental) healthcare research, as online platform owners can decide with which researchers they want to collaborate and in what ways, leading to new types of data haves and have-nots and to different relations between medical and research institutions, on the one hand, and platform owners, on the other. Furthermore, while it may be that online platform owners refuse requests for research to protect online contributors, the insights the latter provide are collected, aggregated and used for various purposes by companies that can afford sophisticated digital data harvesting and processing technologies or even more modest web crawlers (Tiidenberg, 2013). The current situation where platform owners can choose if they allow third-party researchers to study their platform and what shape the study can take, ranging from the mere use of the information already provided by users to more active forms of research, such as online ethnography and interviews, may also threaten scientific quality. In the absence of clear criteria based on which research permission is granted and of clear information regarding the different types of data available and the levels of access to it that exist, the transparency, verifiability, and accountability which are at the heart of sound scientific research become increasingly untenable. It is true that platform owners incur certain risks and have to make various investments to develop and maintain thriving and user-friendly platforms. This makes the question of whether such investments are or should be sufficient to enable platform owners to decide upon the use of information that is produced collectively in the public realm all the more pressing.

The great influence of platform owners is also partially informed by the ineffective or rather outdated informed consent mechanisms that are generally used (Barocas & Nissenbaum, 2014b). These are either too restrictive and superficial, or can hardly be implemented in the highly dynamic online context, where people frequently change their usernames or e-mail addresses, and may give up participation on specific platforms, thereby becoming hard to trace (Michielse, 2015). While solidarity-based forms of consent have been more recently explored (Prainsack, 2019), such attempts need to be furthered and diversified, particularly given the multiplicity of scientific orientations, cultural norms and values that characterize online platforms. These elements are important, because they may influence the preferences online contributors have regarding the types of studies for which they are willing to allow their online insights to be used. Furthermore, new policies and online data regulations need to be developed, both to ensure that the efforts of platform owners are appropriately acknowledged and to reach democratic decisions regarding the extent to which online data that are publicly available can be used, for what purposes, under what circumstances, and through what procedures.

The absence of such regulations leads to various consequences, such as the fact that online information may be re-appropriated and used for aims other than those intended by the people who shared them, including by researchers (Markham, 2016). Another consequence is that scholars engaging with online phenomena come to work in conditions where the status of the data they collect is uncertain and can be unexpectedly modified without them having any say in such processes. Furthermore, the time and effort required to keep up-to-date with the changes online platforms make regarding their data policies may be considerable, especially since typically several platforms are simultaneously studied and very few of them notify users about such modifications. The legalistic phrasing of such terms and agreements hardly encourages repeated readings. While national and international regulations may take longer to develop and implement, providing more appealing and intelligible Terms of Use is an approach that online platforms may want to experiment with, if only to reward through such creative approaches the contributions of the many people who maintain these online spaces alive and thriving through the insights they share.

1.8 Outline

Chapter 2, “The drama of expertise about bipolar disorder online”, sets the scene by describing how two official institutions (one French and one American) have used the internet to share information about bipolar disorder and the challenges that have surrounded these endeavors. In this way, this chapter also provides a more detailed explanation of the usefulness of comparing the French and American mental healthcare approach to bipolar disorder and provides contextual information which will be important to better understand the practices identified in the subsequent chapters. It is also the only chapter in this dissertation which studies how expertise is enacted by two institutions: *The National Institute of Mental Health* (NIMH) in the U.S and *La Haute Autorité de Santé* (HAS) in France. The other three empirical chapters tackle how knowledge is produced online through various individual-group configurations by focusing on the online activities of people diagnosed with bipolar disorder. Since the institutions studied in this chapter are highly authoritative, the analysis is meant to help us understand how expertise is enacted online by influential stakeholders, which possess substantial resources and have numerous options to choose from in terms of online practices. I start by showing that the internet has been perceived as a cost-effective medium to provide health-related information by both governments. I then argue that in sharing information online, these agencies face two types of constraints: (1) regulations demanding such websites to be accessible to people with disabilities; and (2) persistent criticism of psychiatry and ongoing struggles between different types of mental healthcare professionals. I combine insights from Latour (1987) and media studies with a dramaturgical perspective (Goffman, 1959/1990) to analyze the information NIMH and LAS put forward online about bipolar disorder and the online affordances they use in doing so. I show that both stakeholders are rather reluctant internet users, who enact expertise about bipolar disorder online in a highly conservative fashion, which in turn allows them to articulate the knowledge currently available on this condition as stable and precise. While both institutions use similar performative techniques, they adapt them to subtly redefine bipolar disorder in ways which seem better aligned to the priorities characterizing their national health system and their institutional prerogatives and goals.

Chapter 3, “Tactical re-appraisals and digitally-informed hypotheses about the effectiveness of treatment for bipolar disorder”, traces how authoritative medical knowledge, such as that described above, permeates different areas of society, and becomes amenable to multiple usages and interpretations. It explores the internet’s democratizing potential by considering how people diagnosed with bipolar disorder re-appropriate medical perspectives and combine them with personal insights to contribute to the development of new knowledge through dynamic and even fleeting online exchanges on blogs and fora. In so doing, it builds upon insights from medical sociology and STS about patient engagement and contributes to them by describing what the online contributions of people diagnosed with bipolar disorder consist of and how they are contextually shaped. This chapter is based on two types of sources: articles published by scientists in medical journals and data collected from blogs and fora, where people diagnosed shared their treatment experiences. Using de Certeau’s theory (1988) of creative tactics in everyday life, I argue that people diagnosed with bipolar disorder develop more nuanced positions than challenging or accepting medical perspectives online, and engage in productive exchanges. More specifically, the analysis indicates that through their online interactions, people diagnosed move beyond the enactment of lay expertise and collectively generate what I call “digitally-informed hypotheses” in areas where the currently available medical knowledge on the effects and side-effects of medications is insufficient. In so doing, the internet affords individuals diagnosed a voice, yet one which can have a broad epistemic impact only when heard and taken seriously by researchers. Whereas on both American and French interactive platforms advice is sought when one’s doctor is away, in the U.S. there are also contributors who can no longer meet specialists and receive treatment, as they no longer have health insurance. In such instances, these blogs and fora function as alternative means for them to acquire valuable medical information and advice about the ways in which they could access social provisions. This indicates that in certain circumstances, the internet may have modest democratizing effects.

Chapter 4, “Online expert mediators: expanding interactional expertise”, shows that the internet does not always favor the powerful, but this still does not mean that it has a democratizing effect. It traces the online activities of two bloggers diagnosed with bipolar disorder using the concept of interactional expertise developed by Collins and Evans (2002). This chapter argues that by combining medical knowledge with their situated experiences, and by utilizing the affordances of blogs, these bloggers have become a new type of stakeholder, what I call the online expert mediator. This chapter also makes a theoretical contribution, as I extend the notion of interactional expertise by taking into consideration the role of the medium through which interactional expertise is displayed and by showing that its bi-directional character is more substantial than Collins and Evans initially envisaged. The analysis further indicates that the high standing of online expert mediators is not the result of a subversive use of the internet, but of a dynamic alliance with "traditional" experts and of a strong media presence. Since no French counterparts were found for this new type of stakeholder, online expert mediators may denote a possible turn from community activism to exceptional entrepreneurial selves in a society where such approaches have been highly appreciated and encouraged. At the same time, the absence of this new type of stakeholdership in France may also be due to less strained relations between medical professionals and people diagnosed as well as a consequence of French patient associations remaining very influential, managing and organizing the contributions of individuals.

Chapter 5, "Digital biocommunities: solidarity and lay expertise about bipolar disorder", builds upon recent calls made by medical sociologists and STS scholars to focus on the relational character of illness, thereby exploring the internet's potential for solidarity. I start by discussing the different ways in which patients have been conceptualized in recent debates in healthcare and the roles the internet has been ascribed in such discussions. The data used in this chapter were collected from one French forum, and one American forum, and were analyzed through a combination of thematic and conversation analysis. The findings reveal that mental health-related online exchanges enable people diagnosed with bipolar disorder to enact solidarity. This has important epistemic consequences, because online solidaristic practices allow individuals both to enact lay expertise and to contribute to its collective development, as new knowledge is distilled from the personal experiences and insights that are brought together. The description of the main solidaristic practices encountered is followed by a discussion of their potential impacts on the emergence of digital biocommunities. I developed this concept by combining Prainsack and Buyx (2017)'s concept of solidarity with Gershon's (2010) notion of idioms of practice to designate a new type of subgroup, developed not only upon a common diagnosis, life circumstances, experiences, perspectives, and values, but also on similar engagements with the technologies of blogs and fora. By putting forward this concept, I want to highlight that despite an increased focus on individualization in mental healthcare, people diagnosed experience their condition in relational terms, even in regard to lived, embodied experiences.

Chapter 6, "Expertise in the age of big data", brings together the main findings and conclusions that have emerged from the study of the online enactment of expertise about bipolar disorder described in this dissertation. By building upon the theoretical perspectives discussed in this introductory chapter and by combining them with insights acquired from the empirical chapters, I have put forward a new perspective on expertise. This new approach conceives of expertise as a practical and collective achievement realized through coordination and affective labor among stakeholders who occupy multiple and shifting positions within a complex ecosystem. This approach seeks to do justice to the important ways in which cultural and institutional factors shape expertise, while acknowledging the agency and complex identities of relevant stakeholders, who can be in turn or at the same time individuals diagnosed with a condition, professionals, scientific contributors and information mediators. I discuss the significance of the main findings by considering them within the context of broader transformations that digital technologies have contributed to in processes of knowledge production, circulation, and evaluation. In so doing, I argue that we need to move beyond rather simplistic approaches which see the internet either as a quick technological fix or a postmodern version of Pandora's box.

Considering empowerment or active engagement with one's health as merely depending on the availability of information neglects important contextual factors, such as significant differences among people in regard to their needs, perspectives, therapeutic experiences, and engagement with online technologies. Furthermore, the type and quality of health-related information that can be found online as well as the interactive online platforms that one may join are the combined product of previous online practices, personal preferences, and the politics of search algorithms, that not many people are sufficiently aware of. This does not mean, however, that we should fall into the traps of technological determinism and assume that nothing can be done or that people cannot "tweak" the use of this medium to their advantage. The findings presented in this dissertation have also shown, for instance, that people can critically engage and contribute to the development of new knowledge through their specific engagements with the online affordances of blogs and fora. Furthermore, some of them also use the internet to accommodate the informational needs of specific audiences, thereby confirming the necessity for new forms of expertise and (the calls for) the development of new types of professionals in healthcare that other scholars have identified, such as health information counselors and genetic counselors. Through their online engagements, it is not only people's knowledge that is enriched and transformed, but their values and moral precepts as well.

Chapter 2

The drama of expertise about bipolar disorder online

CHAPTER 2

2 THE DRAMA OF EXPERTISE ABOUT BIPOLAR DISORDER ONLINE

The internet has been increasingly used by governments around the world as a cost-effective way to provide health-related information to various audiences (Bennett & Glasgow, 2009; Griffiths et al, 2006; Christensen et al, 2004; Levy & Strombeck, 2002; Barak, 1999). Whereas the U.S. was an early enthusiast and France a relative latecomer, for almost two decades now, important governmental agencies and mental healthcare providers in both countries have been sharing insights about bipolar disorder online. In so doing, they have been confronted with two major challenges. On the one hand, they need to conform with legislation requiring governmental agencies that have online platforms to make sure that the information they share online is accessible to people with disabilities. On the other hand, they are required to make their views public in a context where many people, including mental health professionals, are critical of psychiatry (Morrison, 2013), and where important struggles take place between the different types of professionals involved. This means that the official character of an institution is no longer a sufficient guarantee that the psychiatric insights it provides are accepted as knowledge, so when sharing information online, official bodies need to make proof of their expertise. Using Goffman's dramaturgical approach, in this chapter, I therefore study the performative techniques through which highly authoritative governmental agencies —*The National Institute of Mental Health* (NIMH) in the U.S. and *La Haute Autorité de Santé* (HAS) in France— seek to convincingly enact expertise about bipolar disorder on their online platforms. Given their considerable influence and the high hopes placed on the internet in regard to mental healthcare, understanding the specific ways in which these stakeholders share information online is of great importance. In this sense, Ybarra and Eaton (2005:75) remarked that "investigation of the Internet's applicability as a tool for public mental health interventions is important", while Horst and colleagues (2017:881) noted that nowadays "science communication represents a crucial activity".

First, the context in which the American and the French governments have started to promote the use of the internet as a cost-effective way to provide mental health-related information is briefly discussed. Subsequently, an overview of the two main challenges with which these stakeholders are confronted in their online contributions is provided. I then show that both stakeholders studied here enact expertise about bipolar disorder in a highly conservative fashion. Even though both institutions appear to be reluctant internet users, their selection of rather conservative online affordances combined with specific performative techniques, such as the choice of costumes and stage lay-out, enable them to depict the currently available knowledge on bipolar disorder as stable and precise. While NIMH and HAS use similar performative techniques, they adopt them to advocate different views on bipolar disorder, based on the priorities characterizing their national health systems as well as their institutional goals.

2.1 The internet in mental healthcare in France and the U.S.

As already indicated in the previous chapter, the French mental healthcare system has been undergoing substantial reforms, in order to become more cost-effective. It is against this background that the French authorities started to encourage governmental agencies and health providers to share information online both as a means to educate the general population and to facilitate collaboration between the different types of professionals involved in the provision of mental healthcare. Especially after 2012, the authorities sought to put forward online solutions to reach populations in remote areas, and to prompt people to seek help by providing them with less stigmatizing ways to become informed and to get in touch with medical professionals (eMEN, 2017). Various initiatives and pieces of legislation have facilitated these developments. Important in this sense has been the adoption in 2016 of the law for a “république numérique”, which contains important regulations regarding the online provision of information, greater accessibility, personal privacy, etc. Furthermore, building upon initiatives such as the “digital hospital program” and “Digital Patient Territories”, on July 4, 2016 the French Minister of Social Affairs and Health presented the first national e-health strategy 2020 (Ministère des Affaires Sociales et de la Santé, 2016; VPH Institute, 2016), where the information, participation, and consultation of users were among the highlights. In the same year, France joined the eMEN, a six-country[3] e-mental health project meant to promote the use of innovative digital technologies in the provision of mental healthcare (eMEN, 2017).

In the U.S., the authorities started to look for online solutions in the provision of mental healthcare out of financial considerations and because of a dramatic expected decrease in the number of psychiatrists in the near future, due to retirement and low numbers of student applications in relevant fields. It is in this context that the internet came to be seen as an effective and relatively cheap medium that could be efficiently used

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[3] The other participating countries are the Netherlands (program leader), Belgium, Germany, Ireland and the U.K.

(1) to educate people about metal health in an attempt to prevent and to timely diagnose; (2) to facilitate, expedite, and enhance communication between people diagnosed and medical professionals; (3) to enable access to care for people living in remote areas (Farrell &McKinnon, 2003); and (4) to provide treatment in the form of various online therapies (Barak & Grohol, 2011; Ybarra & Eaton, 2005). Also in this country, such tendencies were encouraged by the development of various strategies and pieces of legislation. For instance, already in 1996, the Electronic Freedom of Information Act (E-FOIA) Amendments mandated that governmental agencies provide information and make their records available in an electronic format (BIS, 2016; Department of Justice, 2014). Aware of people's increasing tendencies to look for information online, in May 2012, the White House launched the Digital Government Strategy, which aimed to further encourage agencies to use information and communication technologies (ICTs). It also provided guidance meant to assist them "to improve digital services and use emerging technologies to serve the public as effectively as possible" (OMB Memo 17-06, 2016). As a follow-up on this strategy, the White House released the U.S. Digital Service Playbook in 2014, which offered 13 main recommendations drawn from successful practices developed in the public as well as private sector (ibid.; The U.S. Digital Service, 2018).

2.2 Technical challenges: accessibility regulations for online platforms

While governmental agencies and mental healthcare providers were encouraged through political and legal measures to share their knowledge online, they also had to observe regulations concerning online accessibility. Worried that online information may not reach people with disabilities, in 1998 section 508 of the Rehabilitation Act of 1973 was amended by the U.S. Congress, requiring all Federal agencies "to make their electronic and information technology (EIT) accessible to people with disabilities." (Section 508.gov, 2017). Importantly, in January 2017, the United States Access Board[4] ruled in favor of updating the requirements for ICTs mentioned under Section 508 and incorporated by reference the recommendations made by several voluntary consensus standards, such as those issued by the European Commission and the Web Content Accessibility Guidelines (WCAG 2.0). The latter are guidelines developed by the Web Accessibility Initiative (WAI) of the World Wide Web Consortium (W3C), which is the most important international standards organization for the internet. This set of guidelines (WCAG 2.0), which became an ISO[5] standard in 2012, addresses new

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[4] The U.S. Access Board is a federal agency that aims to enhance the access of people with disabilities by providing guidelines and standards on various aspects, such as information technology, transportation, medical equipment.

[5] The International Organization for Standardization (ISO) is an international standard-setting body

technologies and focuses not only on the accessibility of people with disabilities but also on that of people using more limiting devices, such as mobile phones rather than computers, laptops or tablets. Building upon an European Parliament resolution from 2002[6], similar legislation was passed in France in 2005. Article 47 of the law no. 2005-102 of February 11, 2005 placed public agencies which shared information online under the obligation to render their websites accessible to people with disabilities. The recommendations inscribed in WCAG 2.0 were taken up in the third version of the Référentiel Géneral d'Accessibilité pour les Administrations (RGAA3), which defines the accessibility regulations that governmental agencies and public service providers in France are legally bound to observe. This document was updated in 2015 from RGAA 2.2, to which all French public websites were obliged to comply by May 2012.

According to WCAG 2.0, websites should be *perceivable, operable, understandable, and robust.* This means that the content put forward should be easy to see and hear, and that any non-text content should be accompanied by text options, which can be more easily accessed using braille or speech, among others. At the same time, websites should be designed so that users can easily find their way around them, the information provided on them should be understandable, and the functions they contain should all be accessible using a keyboard. Furthermore, the content provided on websites should not cause seizures, and the compatibility of online platforms with "future user agents, including assistive technologies" should be enhanced (WCAG2.0). Governmental agencies and mental healthcare providers need therefore to make sure that the information they provide on their online platforms is accessible to people with different types of disabilities, to people with different levels of education, and to people whose modest income may mean that they cannot afford a computer, but can only look up such information using cheaper, less developed, or outdated technologies. While such requirements are necessary and laudable, it is important to note that they place significant constraints on these stakeholders regarding the ways in which they can use the internet and the type of affordances they select for their websites.

2.3 Epistemic and social challenges: critique of psychiatry and divergent interests

While the accessibility requirement set upon governmental agencies and mental healthcare providers has led to challenges of a more technical nature, the public character of the internet has contributed epistemic and social challenges. This second set

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composed of representatives from various national standards organizations, which develops voluntary standards. In March 2017 ISO was working in 162 countries.

[6] The resolution is registered as COM (2001) 529 – C5-0074/2002 – 2002/2032(COS).

of challenges refers to the current context in which NIMH and HAS provide insights about bipolar disorder online, where the authority of such bodies is no longer readily accepted and their recommendations are not taken up without critical consideration. Ever since the advent of the antipsychiatry movement, the expertise and authority of governmental agencies and mental healthcare providers has been challenged in various ways. Antipsychiatry emerged in the 1960s-1970s as a movement which challenged the validity of psychiatric diagnostic and therapeutic practices, considering psychiatry to be an instrument of social oppression and control (Rose, 2018; Castel, 1976). Supporters of the movement further criticized the power imbalance at the heart of all forms of psychiatric treatments and the alienation of medical professionals from their patients. At the same time, many questioned the validity of psychiatric diagnoses, which they saw as arbitrary (McPherson & Armstrong, 2006; Wright & Cummings, 2005) and over-pathologizing (Horwitz and Wakefield, 2007; Scott, 2006), while others denounced the inhumane treatment of people placed in mental hospitals (Morrison, 2013; Gostin, 2008).

The degree to which such critics have opposed and continue to challenge psychiatry has varied as has their identity. Sometimes, criticism has been radical and has included, next to intellectuals, mental health professionals, with psychiatrists such as Szasz arguing that mental illness was a myth, a labelling mechanism through which the social and economic circumstances that dramatically affected people's lives were occluded from view (Szasz, 1961). Other mental health professionals such as Laing sought for a middle ground, founding residential homes and striving to develop more equal therapeutic approaches (Fussinger, 2011; Roberts & Itten, 2006). Similar variety has characterized the responses of people diagnosed, with some wholeheartedly embracing the medical model, with others arguing against specific medical interventions, such as forced containment and electroconvulsive therapy (ECT), and with yet others, ex-patients or self-entitled "survivors" of the mental health system (especially in the U.S.) rejecting the medical model altogether (McLean, 2000).

Some authors (Rissmiller & Rissmiller, 2006; McLean, 2003) suggest that such antipsychiatric tendencies have been transformed and even integrated within the mental healthcare system they were once so critical of, in part due to psychiatry's reaction to the criticism received. Thus, psychiatry embraced a biomedical approach in efforts to render itself more scientific, a growing number of medical professionals started to value the insights of their patients, and the rights of the latter came to be codified in patient charters (Hopton, 2006). Furthermore, antipsychiatry supporters are claimed to have morphed in time into members of the broad consumer movement (Rissmiller & Rissmiller, 2006; McLean, 2003), which argues for the inclusion of people diagnosed in decision-making at all levels, but which accepts the medical model of mental illness.

Such stakeholders are satisfied with the fact that (in principle, at least) people diagnosed have the opportunity to choose the medical professionals they see and also have a say in the treatment they receive. According to proponents of such views, while more radical ex-patients/ "survivors" still exist, a new type of consumer has come into being, who no longer shares the feelings of hopelessness of the ex-patients from the 1970s, nor the latter's strong criticism and suspicion towards mental healthcare professionals.

An overview of books and articles published in the last two decades suggests, however, that such claims about the successful rapprochement between former antipsychiatry supporters and medical institutions underestimate the critical atmosphere which continues to surround psychiatry. Numerous psychiatrists remain critical of their specialty and have come together in various organizations, such as *The International Critical Psychiatry Networ*k, to exchange views and to seek to develop alternatives to the current dominant approach. At the same time, they call for drastic reform of the mental healthcare system, arguing that accessibility and quality of care remain importantly dependent on markers of identity, such as class, race, and gender (Metzl, 2009; Hopton, 2006). Another group of critics accuse current psychiatry of medicalization or imperialistic tendencies, as normal aspects of life and behavior, such as mourning, have become pathologized (Lane, 2009). Other commentators argue that psychiatry has become political to the extent that it puts forward views that have little scientific backing in order to serve particular interests and to uphold certain social values (Wright & Cummings, 2005). Yet others decry the medicalization of mental health conditions, stating that current dominant therapeutic approaches focus solely on medications and neglect social provisions, which are highly necessary for the recovery and social reintegration of people diagnosed (Kinderman, 2014).

Psychiatrists and journalists alike have criticized the close relation between psychiatrists and pharmaceutical companies (Carlat, 2010; Kirsch, 2010; Whitaker, 2010). From this point of view, some deplore the fact that most research on the effectiveness of specific medications is conducted by the pharmaceutical companies themselves, which suggests the results may be biased (Whitaker, 2010). Others downright challenge the effectiveness of medical treatments, arguing, for instance, that there is no significant difference between the effects of antidepressants and those of placebo (Kirsch & Sapirstein, 1998). There are also voices who warn that the promotion of self-determination and empowerment of people diagnosed with mental conditions may be superficial and represent a political move rather than genuine interest and appreciation for their insights (Bernstein, 2006; Hopton, 2006). A staunch opponent of psychiatry remains the *Church of Scientology*, which funds the *Citizens Commission on Human Rights*, the museum *Psychiatry: Industry of Death,* and which disseminates various materials harshly criticizing the effects of psychotropic drugs as well as the motives and intentions of this profession.

Apart from medical professionals, sociologists and journalists, critical psychiatric tendencies continue to be put forward by people diagnosed. From this point of view, the internet has enabled many opponents to come together. According to Whitley (2012:1040), "[t]he Internet has given a means for current and former psychiatric patients, who sometimes refer to themselves as "survivors", to widely disseminate often negative attitudes, beliefs, experiences, and opinions vis-a-vis psychiatry." An example is *The Antipsychiatry Coalition*, an organization which aims "to warn you of the harm routinely inflicted on those who receive psychiatric "treatment" and to promote the democratic ideal of liberty for all law-abiding people" at an international level. They challenge the medical understanding of mental conditions and the scientific bases for the medical treatment prescribed, accusing it to be "quackery", and organize various actions to raise awareness, such as the Electroshock Protest, which took place on May 16, 2015, in the U.S. Highly influential in this sense is also Monica Cassani's blog, *Beyond Meds*. An ex-patient and mental health professional, Cassani claims that this dual position enables her to share "some interesting and sometimes uncomfortable insights into the mental health system in the United States" (Cassani, 2017). Other ex-patients continue to refuse the medical model of mental illness, arguing instead that their experiences represent different ways of being in the world, and such views are promoted by groups such as the *Hearing Voices Network* (Hopton, 2006; Romme & Escher, 1993).

The various types of critique enumerated above indicate that there continue to be important differences even among mental health professionals regarding their understanding and approach to mental health. Such differences of opinion are augmented by the various reforms which have been brought to the mental healthcare system in both countries (Hochmann, 2017), as by limiting insurance coverage and the number of (prospective) specialists, these reforms have led to the marginalization of previously successful professionals, such as psychoanalysts in France. Furthermore, the dire competition for federal and governmental funds leads different types of mental healthcare professionals to embrace divergent interests and to advocate different approaches. For instance, psychologists often reduce psychiatry to the mere provision of medical treatment and accuse it of neglecting the full person of the person diagnosed. Moreover, by focusing too much on genetic and neurological factors, psychologists and social therapists argue that important environmental factors are neglected. In their turn, psychiatrists answer to the accusation that they merely prescribe psychotropic drugs by pointing to general practitioners as the professionals who often prescribe higher dosages and more medicines than they recommend. As a reaction to extreme biomedicalization, psychoanalysts seem to be making a come-back in the U.S., even though access to them is heavily restricted by insurance policies (Maness, 2017; O'Sullivan, 2016; Chessick, 2006). In France, the conflict between psychoanalysts and psychiatrists is still fresh. For instance, a report from 2009 for the Minister of Health and Sports, Roselyne Bachelot, where three approaches to mental health were evaluated, caused a lot of uproar. At a more general level, mental healthcare providers decry the influence of managed care controls and the cost containment policies which have been taken up over the last decades, and which severely reduce their autonomy and ability to make treatment decisions freely (Scheid, 2000).

As a result, it becomes clear that the online provision of information about bipolar disorder by governmental agencies and mental healthcare providers takes place in a context fraught by important challenges, as many remain suspicious of psychiatry, and different stakeholders continue to hold different views on the causes of mental conditions and the best therapeutic approaches available. At the same time, since both the French and American mental healthcare systems have been undergoing important transformations, different types of mental healthcare professionals often find themselves in competition for limited resources or have to take over functions and tasks previously fulfilled by other specialists (Gill et al, 2014; Desmettre, 2009). Succeeding to enact expertise about bipolar disorder online in such a fraught context becomes therefore a rather remarkable feat, which needs to be carefully studied.

2.4 Theoretical and methodological approaches

In the field of STS there is a rich tradition of studies on the construction of scientific knowledge (Knorr Cetina, 1999; MacKenzie, 1990; Shapin & Schaffer, 1985/2011), whereby the importance of social, political, economic factors in processes which for a long time have been claimed to be neutral has been highlighted. In this sense, Felt remarked that "[m]aking knowledge is …never an 'innocent' activity; nothing can be regarded as 'natural' or 'simply given'" (Felt, 2017:253). Important to understand the work that goes into the construction of scientific facts is the work of Latour (1987), who shows that "science in the making" is messy, subject to heated debates and controversies, which are often solved by making strategic alliances or by using one's social capital (Bourdieu, 1975). This chapter studies how governmental agencies enact expertise about bipolar disorder online, which means that it does not deal so much with the construction of scientific facts, as it traces the manners in which they are made available online, their unfolding destiny on these platforms. For this purpose, I have combined insights from Latour on the rhetorical techniques through which scientific facts are constructed with the notion of performance developed by Goffman, described in more detail below, and with perspectives from media studies on the role of various web interface elements on users' experiences. This combination strengthens my analysis by allowing me to move beyond rhetoric and to consider the online technologies these institutions use and the online practices they engage in to foreground particular insights about bipolar disorder while downplaying others. It also enables me to pay particular attention to how web design elements contribute to the production of meaning.

NIMH and HAS need to share information about bipolar disorder in a persuasive way online in order to educate the public and facilitate the provision of mental healthcare. This makes Latour's emphasis on the important role rhetoric plays in the complex trajectory statements follow from mere hypotheses or "hunches" to scientific facts highly relevant for this analysis. Latour highlights the use of positive or negative modalities, which imbue statements with lower or greater degrees of certainty, contributing to their solidification into facts or to their dissolution into fiction. Successful use of positive modalities leads to scientific facts. Yet before reaching such a felicitous state, statements need to face more or less influential detractors, are endangered by competing theories or by the risk of research funds being suddenly terminated. Tellingly, Latour remarks that "the construction of facts ….is a *collective* process" (1987:29), as the fate of statements is in the hands of those who take them up, invoke them, re-use them. When the status of a statement is debated, various rhetorical techniques are used in their support, such as the argument from authority, where one's status and prestige are invoked to render one's claim more credible; the context of citation, through which arguments from other sources are acted upon to better serve one's claim, divide et impera, where opponents are shrewdly set against each other, as well as one's ability to ensure that one's claim is not ignored and that it will be referenced by others in the future. In an earlier work, Latour and Woolgar (1979) have highlighted the important role images play in stabilizing facts, which is a significant aspect considering the visual nature of the online materials studied here. In studying how governmental agencies and healthcare providers enact expertise about bipolar disorder online, I retain from Latour the sensitivity to rhetorical techniques. Despite their obvious merits, Latour's insights focus on the construction of scientific facts in the context of a small, select audience, formed by specialists with relatively similar levels of education, views, and values. They are not sufficient to trace the destiny that awaits scientific facts once they enter the public domain, nor do they sufficiently account for the specificity of the medium through which they are transmitted. I use therefore a theoretical framework which combines the rhetorical techniques highlighted by Latour with the concept of performance put forward by Goffman (1959/1990), as it allows me to better focus on the techniques through which scientific information and the public image of influential stakeholders are shaped and managed for broader, diverse audiences. In so doing, I build upon insights put forward by Hafermalz and colleagues (2016), who argued in favor of using Goffman's dramaturgical approach to study the sociomateriality of various phenomena encountered in information systems.

According to Goffman (1959/1990), social interactions represent performances through which individuals seek to produce desired impressions on their audiences by engaging in various practices of self-revelation and concealment. Goffman (1959/1990) lists several elements which contribute to the success of a performance: *the team and team-mates* who put up the performance, and who can take up different roles, i.e., director, actors; *the setting*, that is, the environment where the performance takes place; *sign-equipment* consisting of various props that help foster the impression intended by the performance, and *the audience*, consisting of those for whom the performance is put up. In order to guarantee the success of their performance, actors have to engage in information control, seeking to ensure that what the audiences see and hear is in line with the overall message of the performance. Important for such purposes is the division of the stage upon which the performance takes place into two regions – the front and backstage- which can be accessed by different people and where different behaviors can be taken up. Whereas the frontstage refers to the totality of actions and props that the actors engage with and use in their performance that are visible to the audience, the backstage refers to the elements that one needs to occlude from view in order to guarantee a successful performance, to information to which the audience's access is purposefully impeded. Despite such measures, in Goffman's understanding, a successful performance also depends on the good will of the audience, who agrees to be seduced into accepting the vision of reality put forward through the performance and who, for this purpose, sees and hears selectively.

Building upon Goffman, I analyze the online platforms of governmental agencies and mental healthcare providers as performances through which they seek to successfully enact expertise about bipolar disorder by using various dramaturgical resources. Using the concept of performance in this context has the advantage of revealing the dynamism at work behind that which appears to be static and unproblematic, and it also enables one to take a perspective through which that which may seem familiar is transfixed, thereby revealing hitherto less noticed aspects. In so doing, I follow in the footsteps of other sociologists of science, who have taken a dramaturgical perspective to better understand how scientific credibility is produced, maintained, and contested (Bijker et al, 2009; Jasanoff, 2004; Hilgartner, 2000). The use of the concepts of "performance" and "enactment" in the same study might seem problematic, since some scholars (Barad, 2003) have understood performance in a very limited way, as something akin to engaging in an activity, whereas others (Mol, 2002) have preferred the notion of "enactment" as it did not carry within it the implicit distinction between a real self/"persona" or inner identity vs. a "mask" or external identity. I use here the understanding of Goffman's notion of "performance" put forward by Hafermalz and colleagues, who see it as "collective work that goes into sustaining [a particular version of] reality" (Hafermalz et al, 2016:9). This understanding allows one to focus not only on the particular actions through which this version of reality is successfully put up and maintained, but also on the activities that could disrupt it. Enactment thus encapsulates multiple performances, which may be spread across myriad settings, involve different actors, and types of sign-equipment.

The type of information about bipolar disorder that the two stakeholders studied here choose to share online and how they do so not only influence the ways in which this condition is understood by their readers, but also affects their credibility and standing. From a dramaturgical point of view, these institutions are therefore performers who seek to convince their online audiences that they are in fact endowed with expertise, that the knowledge they dispose of is substantial, esoteric, and reliable. Scientific facts about bipolar disorder and recommendations regarding best diagnostic and treatment practices do not simply appear before the audience; instead they are put together in particular ways by different actors, using various rhetorical strategies, so that they can best fit the narrative about bipolar disorder they want to put forward. As knowledge about bipolar disorder is not produced at an extremely rapid pace, different actors often need to use the same information, to frame it and reframe it in order to align it with their overall purposes as well as with the public identity they seek to project. While the concept of performance highlights the intentionality and agency of those undertaking it, it is difficult to tell how the information put forward online has come into being, who has authored it and under what circumstances.

The governmental agencies studied declined a request to conduct interviews in order to find out more about their decision-making processes in this respect, which limited the analysis to data that were publicly available. Nevertheless, the influence and highly public character of NIMH and HAS combined with the complex use of the internet for mental health-related purposes leads me to expect that considerable attention has been paid to the type of information shared online. This is likely to be the case in the U.S., country with rather pronounced litigious tendencies. Furthermore, since HAS is the authority in charge of providing the HONcode[7]certification for health-related online platforms in France, it is likely that it pays great attention to the information it shares on its own website. While the absence of interviews and the lack of access to the internal documents of these institutions means that I could only study their frontstage, the comparison of the information on bipolar disorder made available online at different moments in time enabled me to identify novel elements entering the frontstage as well as insights and perspectives which were downplayed or given up upon. I therefore suggest that in the case of online performances, there may be two types of backstage worth

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[7] The Health of the Net Foundation Code of Conduct is a form of certification available only for online platforms dedicated to health-related issues, which indicates that the information provided is credible and reliable.

considering: the "conventional" one that Goffman (1959/1990) described, containing interactions and negotiations among the online platform developers, debates among scientists, drafts of the information intended to be made available and the tools and technologies used for these activities; and a "digital" backstage, containing previous versions of the performance, which can reveal, through comparison with the current performance, elements which the team may seek to conceal. Whereas access to the first type of backstage was not allowed, the "digital" backstage could be visited by collecting and comparing data from the online platforms at three different moments in time. Data for this study consist therefore of the online pages dedicated to bipolar disorder on the website of NIMH and HAS and they were collected in 2014, 2015 and 2016.

The success of a performance does not only depend on the talent of the actors and the quality of their parts, but it is also importantly shaped by the stage decorum. Insights from media studies reveal that elements of visual design importantly shape the meaning of the information made available on an online platform. Thus, the quantity of information provided on a particular aspect, where the information is placed on a website, the font size and type, how the information is visually framed by banners and advertisements, a dynamic or static environment, the type and position of the menu as well as the writing style used guide readers towards particular bits of information, and help them distinguish important insights from less relevant ones (Moshagen & Thielsch, 2010). The use of color is also very important, as color patterns help readers recognize how information is structured and organized, the contrast between foreground and background importantly affects a website's readability, while the number and kind of colors used and their distribution on the website affect readers' ability to concentrate and may imbue the information with particular connotations (Cyr & Trevor-Smith, 2004; Flemming, 1998). Next to these elements, the navigability of an online platform and the affordances available to their users importantly shape users' attitude towards the insights provided. Given the important role they play in the production of meaning and the great variety of ways in which they can be combined online, these elements were also considered when analyzing how NIMH and HAS enact expertise about bipolar disorder online. The data collected consist therefore of texts, videos, images, and hyperlinks and were analyzed using thematic and semiotic analysis.

2.5 Performative techniques and online expertise about bipolar disorder

2.5.1 NIMH and the quest for the redefinition of bipolar disorder

NIMH is the main agency of the American government responsible for biomedical and mental health-related research. It is also the largest research organization in the world focusing on mental health. With a budget of about $ 1.5 billion, NIMH conducts its own research, but also largely determines the national research agenda by providing grants to other institutes and organizations throughout the U.S. In what may be seen as an attempt to counter anti-psychiatric tendencies, since the 1980s, NIMH has also started to pay more attention to the perspectives and insights of people diagnosed with mental conditions. For instance, it has funded self-help agencies managed by former patients or self-titled "consumers", which nowadays together constitute *The Center for Mental Health Services*. At the same time, NIMH has launched two research centers with the task to study the activity of self-help groups and the (therapeutic) effectiveness of such initiatives among people diagnosed with severe mental health conditions (Borkman, 1997). Important to understand the highly influential position NIMH occupies is the distinction between being "in authority" and being "an authority" put forward by Jongen (2017). Being *in* authority refers to the mandate certain governmental bodies receive to develop rules and regulations and even to make decisions for others. Being *an* authority is linked to the epistemic authority of certain institutions or people, and highlights the relation between the bearers of such authority and those who grant it. NIMH is therefore both in authority, by actively shaping the activities of numerous institutions and self-help groups, and an authority because of the prestige it enjoys. Furthermore, it is endowed with sufficient resources to shape its online presence as its representatives best see it fit.

The most important finding regarding the ways in which NIMH shares its insights about bipolar disorder online is this institution's efforts to redefine bipolar disorder. These are revealed in various twists brought to the plot of bipolar disorder as it is recounted in the monologue of the main actor, who is dressed up in the costume of digital text. According to NIMH (2014, 2015, 2016), "[b]ipolar disorder, also known as manic-depressive illness, is a brain disorder that causes unusual shifts in mood, energy, activity levels, and the ability to carry out day-to-day tasks." While the members of the audience attending the performance for the first time may not be aware of it, with this definition, NIMH embarked upon the process of redefining this condition. Bipolar disorder is generally considered to be a "mood disorder". Yet NIMH, the most authoritative institution studied in this dissertation, is the only actor to firmly redefine bipolar disorder as a "brain" condition, thereby singling out what it considers to be the main cause of a condition where genetics, heredity, hormones, and environmental factors are all thought to play a significant role. That NIMH engages in such a definition is not accidental, given the strong biomedical trend characterizing American psychiatry, the constant pressure for mental conditions to be diagnosed according to measurable, quantifiable tests, as well as NIMH's own identity as a funding agency.

In order to accomplish this redefinition, NIMH needs to modify the weight that has thus far been ascribed to various markers of bipolar disorder. Important in this sense is its broadening of the definition of a mood episode to include next to examples of various emotional states (2014) also descriptions of different levels of energy and types of behavior (2016). Thus, rather than acknowledging mood shifts as the most important indicators of this condition, NIMH brings them on a par with other aspects, such as one's levels of energy and activity, and one's ability to fulfill daily functions. In so doing, NIMH puts forward a more complex image of bipolar disorder, which is importantly tied to a person's ability to engage in various acts. This change brings with it important modifications in the ways in which bipolar disorder is diagnosed, as medical professionals need to assess a person's behaviors along several dimensions, but also in the ways in which people diagnosed with this condition relate to it. Thus, bipolar disorder is turned into a condition which is not only known from the inside, by the person experiencing particular emotions, but also into one which can be more easily monitored from the outside, even in the absence of highly deviant behaviors, and, importantly given the latest tendencies, along quantifiable markers. While such a redefinition brings new aspects of bipolar disorder to the fore, it also succeeds in relegating to the backstage other important elements.

In redefining bipolar disorder, NIMH combines selective concealment of alliances and interests with the provision of very general information. Thus, describing bipolar disorder as a brain condition favors a neuroscientific approach to it, yet NIMH does not discuss the implications of its definition, nor does it share any details regarding the type and amount of scientific evidence which led it to this conceptualization. Instead, it simply puts forward this perspective, thereby manifesting its awareness that it has enough authority for it to be seen by others as credible, legitimate. Importantly, this also shows that NIMH enacts expertise about bipolar disorder through statements and pronouncements in ways which make it seem rather oblivious to the distrust some people experience in regard to psychiatry and governmental institutions. Nor does it publicly consider how such a redefinition may impact upon the wide array of mental health professionals involved, what people diagnosed with bipolar disorder feel about this new causal focus, and how it will affect social provisions. All these are issues that NIMH keeps backstage, successfully occluding them from view in its performance.

Having opted to dress its main actor in the modest costume of online text allows NIMH to put forward a depiction of knowledge about the basics of bipolar disorder as stable and orderly. Thus, it does not emphasize the novelty that this definition brings into the study and diagnosis of this condition, nor does it indicate when and what kind of information is modified on its website. Yet, a look into the backstage of its platform, that is, at records of the information previously available on its main page dedicated to bipolar disorder, reveals that in 2014 NIMH was more optimistic about genetic causes, dedicating more space to their discussion. Nor did it hesitate to suggest bipolar disorder may be a condition occurring in families:

Table 2.1 Excerpts on bipolar disorder from NIMH's online platform

NAME INSTITUTION & YEAR	ONLINE TEXT
NIMH 2014	Bipolar disorder tends to run in families. Some research has suggested that people with certain genes are more likely to develop bipolar disorder than others. Children with a parent or sibling who has bipolar disorder are much more likely to develop the illness, compared with children who do not have a family history of bipolar disorder. However, most children with a family history of bipolar disorder will not develop the illness. (…) But genes are not the only risk factor for bipolar disorder. Studies of identical twins have shown that the twin of a person with bipolar illness does not always develop the disorder, despite the fact that identical twins share all of the same genes.
NIMH 2016	Some research suggests that people with certain genes are more likely to develop bipolar disorder than others. But genes are not the only risk factor for bipolar disorder. Studies of identical twins have shown that even if one twin develops bipolar disorder, the other twin does not always develop the disorder, despite the fact that identical twins share all of the same genes.

While the use of present tense in the first sentence of the fragment from 2016 reinforces the validity and actuality of research claims that genetic causes are determining factors in the development of this condition, the direct link to bipolar disorder's occurrence in families is downplayed. Thus, the first three sentences which reinforced this idea in 2014 have been removed in 2016, when the text becomes much shorter and the word "family" disappears, the reference to it in the construction "people with certain genes" becoming thus significantly weaker. The 2016 text may be seen as an attempt to preempt alarm among the relatives of people diagnosed with bipolar disorder and its brevity suggests that NIMH may have assumed this information not to be particularly interesting for its audience. The use of indefinite adverbs and adjectives, such as "some" and "certain", and the absence of any references does not encourage the audience to look further into these matters. The audience is therefore expected to believe these statements simply because they have been uttered from a place of authority. Furthermore, the older information is not available to all the visitors on NIMH's website. While it makes sense to retain on it the most up-to-date insights, doing so in the absence of any discussion as to the processes and evaluations whereby such modifications take place and without any indication as to when such modifications are made promotes an image of NIMH's expertise about bipolar disorder as unquestionable and unmodifiable. At the same time, it conceals the dynamic ways in which the institute adapts its orientation as to the most fruitful areas of research into the causes of bipolar disorder. Furthermore, it does not allow readers to become aware of the role factors such as scientific feasibility, the great popularity and influence of specific scientific fields or scientists, available technologies, financial costs, administrative and organizational obstacles play in such processes of (re) definition. For instance, the information NIMH displayed in 2017 did not indicate to what extent advances in neuroimaging technologies and techniques contributed to its supporting the idea that "the brains of people with bipolar disorder may differ from the brains of healthy people or people with other mental disorders" (NIMH, 2017).

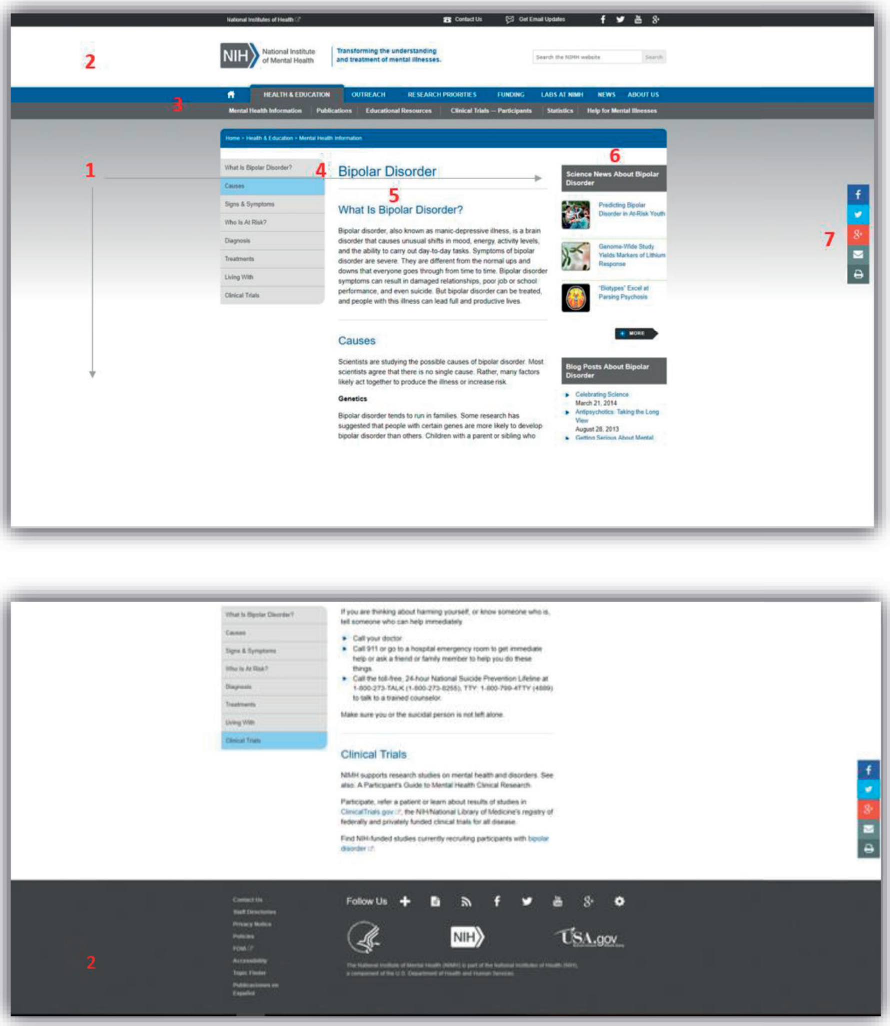
It is important to mention, however, that as NIMH redefines bipolar disorder by positioning it in the brain and by translating it into a set of parameters about one's levels of activity, it becomes more modest about the knowledge claims that can be generally made about the causes of this condition. Thus, whereas previously its views concerning the determining factors for bipolar disorder were organized under the rubric "Causes" (2014), nowadays the rubric has been renamed "Risk Factors" (2016). And while the notion of "cause" suggests that one understands sufficiently well a phenomenon to be able to trace its various manifestations to the factor(s) generating it, the term "risk" denotes the limited or incomplete character of the available knowledge.

Even though its performance is mainly intended for the general population, the insights shared by the main actor are of great interest also to medical professionals, especially since NIMH is the largest institute for funding mental health research. Thus, its redefinition of bipolar disorder not only has performative effects at the level of the audience, but will most likely shape the course of research into this condition for the coming years. At the same time, NIMH's authority and legitimacy allow it to believe that its conceptualization of bipolar disorder will be taken up by medical professionals, academics, researchers applying for funds, thereby further heightening the scientific character of the definition they put forward. NIMH's prestige and influence make it likely that not only its scientific views will be adopted by other stakeholders, but also its use of the internet. There is, however, a stark contrast between NIMH's activities as a funding agency, which sponsors highly innovative studies on bipolar disorder, and the type of online platform they have opted for. NIMH's website is not interactive, and the audience is thus prevented from directly and publicly challenging the performance this institute puts up. In so doing, NIMH limits the extent to which the audience can directly influence its performance and threaten the version of bipolar disorder it puts forward. But it also prevents people from learning about this condition in novel and more social and/or playful ways. From this point of view, its rather conservative choice of online platform is less than what could be expected from an institute which promotes education and innovation.

2.5.2 The role of sign equipment in NIMH's performance on bipolar disorder

As already mentioned in the previous chapter, the type of platform a particular stakeholder chooses depends on its status, on the resources it has available, and on its goals. From a financial and technical point of view, noninteractive online platforms are less challenging, as they represent variations upon options which have been available since the early days of the internet. Considering the relatively simple technologies and programming functions required for their development as well as their limited interactive potential, noninteractive online platforms may be seen as rather conservative options in the current digital environment. They are hardly ideal for governmental agencies which aim to educate their audiences and encourage them to use (certified) online resources. Furthermore, in a context where such official bodies find themselves under the obligation to have an online presence, opting for a non-interactive online platform does not help them position themselves as open and transparent. Nevertheless, such platforms continue to be the preferred choice for many official institutions, which seem to be more interested in making information available to the public rather than also acquiring direct insights into the public's views and experiences. NIMH has opted for a noninteractive online platform, and its considerable budget suggests that this choice was motivated by other reasons than financial concerns. If we look at the information NIMH provides on its online platform as a performance, then the visual, structural, and functional aspects of the site (see Fig.1) represent important elements of the sign equipment used, which are meant to contribute to a persuasive performance. The ways in which information is structured and organized on the platform together with the choices that were made regarding webpage and navigation design are relevant, because they help orient the audience towards particular understandings (Djonov, 2007).

Figure 2.1 Images of the upper and lower part of NIMH's website (2016)



Bipolar Disorder

What Is Bipolar Disorder?

Bipolar disorder, also known as manic-depressive illness, is a brain disorder that causes unusual shifts in mood, energy, activity levels, and the ability to carry out day-to-day tasks. Symptoms of bipolar disorder are severe. They are different from the normal ups and downs that everyone goes through from time to time. Bipolar disorder symptoms can result in damaged relationships, poor job or school performance, and even suicide. But bipolar disorder can be treated, and people with this illness can lead full and productive lives.

Causes

Scientists are studying the possible causes of bipolar disorder. Most scientists agree that there is no single cause. Rather, many factors likely act together to produce the illness or increase risk.

Genetics

Bipolar disorder tends to run in families. Some research has suggested that people with certain genes are more likely to develop bipolar disorder than others. Children with a parent or sibling who

If you are thinking about harming yourself, or know someone who is, tell someone who can help immediately.

- Call your doctor.
- Call 911 or go to a hospital emergency room to get immediate help or ask a friend or family member to help you do these things.
- Call the toll-free, 24-hour National Suicide Prevention Lifeline at 1-800-273-TALK (1-800-273-8255); TTY: 1-800-799-4TTY (4889) to talk to a trained counselor.

Make sure you or the suicidal person is not left alone.

Clinical Trials

NIMH supports research studies on mental health and disorders. See also: A Participant's Guide to Mental Health Clinical Research.

Participate, refer a patient or learn about results of studies in ClinicalTrials.gov, the NIH/National Library of Medicine's registry of federally and privately funded clinical trials for all disease.

Find NIH-funded studies currently recruiting participants with bipolar disorder.

The National Institute of Mental Health (NIMH) is part of the National Institutes of Health (NIH), a component of the U.S. Department of Health and Human Services.

Table 2.2 highlights some sign equipment elements and gives a brief overview of the specific roles they play in NIMH's performance.

Table 2.2 NIMH: Stage lay-out and its performative effects

ELEMENTS	DESCRIPTION	RHETORICAL / PERFORMATIVE EFFECTS
1	Top-down, left-right navigation	Enhanced readability & comfort; attempts to steer the behaviors of the audience
2	Top banner with the logo of the institution; Bottom banner with information about the institution	Self-presentation (content) Encasing & highlighting the most important information (position)
3	Dropdown navigation bar, horizontally organized, situated on top of the page	Enhancing the platform's navigability in view of multiple audiences
4	Rubrics on bipolar disorder on the top left corner of the page	Sign-posting the organization of the content & the elements taken into account
5	Main content on bipolar disorder in the main viewing area	Signaling the most important information
6	News, blog posts, enrolment in studies, access to publications, and research results vertically organized, on the right side of the page	Self-presentation: dedicated to science & supportive of public engagement Bipolar disorder research: dynamic & fruitful
7	Online affordances for audience to use & share the content	Highlighting the importance of the content & restricting the audience's reactions to areas outside the platform

As can be seen in Figure 2.1, NIMH has opted for a rather minimalist visual design of its online platform. Blue and grey are the main colors used and they fulfill important functions, as they highlight specific rubrics or content. The choice of colors is in line with the WCAG 2.0 recommendations, which mention that a good distinction between foreground and background enhances readability. By choosing to give its performance in a minimalist *setting*, NIMH reveals its awareness of the highly authoritative position it occupies, of the fact that it does not need to use any apparent embellishments in order to draw crowds in for its performance. Furthermore, this apparent simplicity may fulfill another important rhetoric function, as it seeks to convey to the audience the message that the performance aims to reveal the truth about bipolar disorder without any artifice and in an unbiased fashion. The sober colors used on the platform together with the basic affordances are meant to be a visual enactment of scientific rigor and authority.

At the same time, the audience is steered this way to focus on the content it makes available, to engage with the information about bipolar disorder.

While the visual design of the site is how NIMH chooses to decorate the stage for its performance, I consider the platform's rubrics to be stage props, which contribute to the institution's self-presentation and reveal the targeted audience and the type of relation NIMH envisages with it. Thus, the information it makes available about bipolar disorder is placed under the more general rubric entitled "Health & Education", which indicates that the insights provided are meant for the general population and not for mental healthcare professionals. In so doing, NIMH seems to be positively responding to the various measures taken by U.S. authorities to encourage the use of the internet for mental health-related education. The horizontal rubrics at the top — Mental Health Information; Statistics; Consumer Health Publications; Help for Mental Illnesses; Clinical Trials — bring together different types of knowledge and reveal NIMH as an institution devoted to furthering scientific knowledge while being appreciative of the insights put forward by people diagnosed with mental conditions. At the same time, these rubrics remind the audience that the institute is not only dedicated to research but also to improving the lives of people diagnosed.

While the rubrics at the top of the website serve self-presentation purposes and focus on the institute's missions and prerogatives, those in the lower part of the page reveal how it uses its online platform. Thus, they contain brief clarifications regarding NIMH's position on FOIA, accessibility, privacy, its policies, and the ways in which it can be contacted. Regarding accessibility, NIMH assures its readers that it "is making every effort to ensure that the information available on our website is accessible to all. To meet this commitment, we have designed our site to comply with Section 508 of the Rehabilitation Act." Nevertheless, NIMH reserves for itself the right to decide how to enact this commitment. Thus, while the static character of its website facilitates its accessibility, it does not provide text-alternatives for some of the videos put up. From this point of view, it would appear that NIMH uses the accessibility guidelines in ways which allow it to opt for the platform design and online affordances that it prefers.

Revelatory insights regarding the goals of the performance NIMH puts up and about its intended audience are provided under the rubric "Policies". Thus, NIMH states that it

> does not intend to provide specific medical advice on our Web sites, but rather to help visitors better understand mental health and disorders. NIMH will not provide specific medical advice and urges you to consult with a qualified mental

> health or health care provider for diagnosis and for answers to your personal questions.

The information provided under these rubrics is therefore highly important, as it reveals that NIMH uses its online platform to educate the general population rather than target medical audiences. At the same time, it shows that in managing the information it shares online, NIMH takes care not to jeopardize or diminish the authority and prerogatives of medical professionals.

In line with these goals and with its intended audience, NIMH has opted to dress its *main actor* in the rather conservative *costume* of online text provided on a noninteractive platform. No further details are given regarding the designer(s) of this costume, when it was produced and how. Building upon Latour's (1987) insights, this choice may have been informed by NIMH's desire to highlight the scientific character of the information it provides by rendering it "devoid of any trace of ownership, construction, time and place" (Latour, 1987:23). Dynamism on stage is created through the efforts of *side actors*, who compete for the attention of the audience, and serve as reminders of NIMH's prerogative and dedication to tackle the complexity of bipolar disorder. At the same time, the dynamism of the videos and hyperlinks seems to emphasize even more the stability and importance of the main actor. While the audience cannot interact with the actors, they may choose to print the information made available, e-mail it, or share it on social media. This way, NIMH seeks to limit the audience's role in the performance, as it restricts its ability to publicly challenge in the same online space the vision of bipolar disorder it puts up. Thus, the online affordances available for the audience are rather conservative, in the sense that they do not allow the intended audience to engage closer in processes of knowledge production and evaluation through direct reactions, accessible to all. Even though these online affordances are common elements on most websites nowadays, they still fulfill a performative function, as they suggest that the knowledge made available is relevant and interesting enough for people to want to keep it or to inform others about. Importantly, two supporting actors dressed up in hyperlinks invite the audiences to join studies developed by NIMH. Thus, while NIMH is rather conservative in the ways in which it enacts expertise, it does use the latest approaches to online technologies when they serve its purposes.

The simplicity and clarity of the platform is aligned with the ways in which the part of the main actor is structured and worded. Thus, NIMH's perspective on bipolar disorder is organized along the following rubrics: definition; signs and symptoms; risk factors; treatments and therapies; join a study; learn more. As these rubrics already suggest, the information provided contributes to a performance whereby bipolar disorder is presented as a complex, but manageable condition, and a hopeful, optimistic tone is maintained by mentioning ongoing studies meant to set further light onto its causes and reveal fruitful new forms of treatment. The vertically-organized rubrics on the right play an important role in supporting this perspective, as they help convey a dynamic view on research on bipolar disorder, whereby new insights are frequently put forward and new studies are available for people to join. At the same time, the limited and rather general character of the information provided makes it less open to challenges. Thus, it is rather obvious that NIMH uses its main online page on bipolar disorder first and foremost to educate its readers, and that it also hopes to enroll study participants this way. The peripheral position ascribed to the option "Contact Us" suggests that dealing with public inquiries is not a function NIMH is eager to engage with. Overall, by using Goffman's dramaturgical approach, it has become possible to highlight some specific ways in which the (visual) design of NIMH's online platform and the online affordances available on it participate in shaping the meaning of bipolar disorder as well as the institute's public image. Sharing information online requires important coordination work between distinct elements. It may also involve some difficult choices between sharing knowledge in an authoritative fashion and using digital design options and online affordances in more innovative ways, which allow the audience a more active role in the production and evaluation of knowledge, not only in its further dissemination.

2.5.3 HAS's performative techniques to redefine bipolar disorder

HAS is an independent public institution with a scientific character, created in 2004. Its board consists of eight members appointed for six years (with the possibility of renewal every three years) by the President of France (two members can be proposed by the President, two by the President of the Senate, two by the President of the National Assembly, and two by the President of the Economic, Social, and Environmental Council (CESE). HAS fulfills three main functions: (i) to evaluate from a medical and economic point of view health products, technologies, and practices in view of their admission for reimbursement (a French version of Health Technology Assessment); (ii) to provide recommendations on healthcare practices and public health; to create guide books on treatment for patients and medical professionals; to develop medico-economic studies; to advise public institutions in their decisions regarding public health, and to define the trajectory of personalized care to which one is entitled; (iii) to certify healthcare establishments and to provide accreditations for medical professionals. Very important for this project is that HAS also certifies health-related online platforms. Its current annual budget is €60 million, and its revenue comes from taxes on promotional spending by drug companies, from National Health Insurance, state funding, HONcode accreditation fees, payment for assessing applications for inclusion on reimbursement lists, etc.

In a way reminiscent of NIMH's approach, HAS succeeds through its recommendations of diagnostic and therapeutic practices to redefine bipolar disorder online. Such developments take place on a stage, where three main actors share their insights (see Figure 2): (1) a storyteller that informs the public about the aims with which HAS developed the memo card and the audience it addresses; (2) a main character, the memo card, which consists of an overview of practices meant to help doctors diagnose and treat bipolar disorder efficiently and effectively; (3) another main character, the report on the elaboration of the memo card, which effectively takes the audience backstage, revealing the processes and negotiations through which the memo card came into being. While HAS shares with NIMH the use of the performance of their main characters to modify the meaning of bipolar disorder, it differs from NIMH in the approach to bipolar disorder it takes up, as it focuses on its "evolution" in time, constructing it as a developmental or degenerative condition. HAS states, for instance, that the periods of remission between episodes get shorter in time, especially if bipolar disorder is not treated, whereas the number of depressive episodes become more frequent and last longer. In so doing, HAS highlights the importance of correctly diagnosing this condition as early as possible, it signals its severity, and also emphasizes the importance of treatment. At the same time, HAS heightens the pressure medical professionals are under in order to correctly identify bipolar disorder. Such a redefinition may therefore be a performative technique through which HAS seeks to achieve one of its stated goals, namely to reduce diagnostic delay (HAS, 2015a).

This aim sets the stage for the most dramatic twist in the performance of expertise about bipolar disorder HAS puts up, as it emphasizes the link between this condition and suicide. HAS frames suicidal attempts as symptoms of bipolar disorder, mentioning that this condition is "a highly suicidogenic pathology" (2016). Warning about the severity of this risk, the main actor calls upon various statistics in order to legitimize this perspective. It states, for instance, that one out of two people diagnosed with bipolar disorder will make at least one suicide attempt and that at least one out of ten untreated patients will commit suicide, which accounts for 15% of the population of people diagnosed with this condition. Statistics have the merit of conferring an aura of objectivity and credibility to the information provided, making it seem more factual and, in this particular case, more urgent (Potter, 1996). From this perspective, the performance HAS stages is also meant to reinforce its institutional role, as it guides medical professionals in the correct assessment of the suicide risk their patients pose. HAS does so by developing indicators which are specific to bipolar disorder: an early onset of the condition; the presence of mixed characteristics; rapid cycles; the presence of psychotic symptoms; alcohol addiction; addiction to illicit substances or to other psychoactive substances.

Figure 2.2 Images of the upper and lower part of HAS' online page on the diagnosis and treatment of bipolar disorder

Fiche Mémo

Patient avec un trouble bipolaire : repérage et prise en charge initiale en premier recours

Objectifs : L'objectif de cette fiche mémo est d'aider les médecins assurant les soins de premier recours à :

- Améliorer le repérage des patients adultes et adolescents souffrant d'un trouble bipolaire.
- Améliorer par un repérage précoce la prévention des complications des troubles bipolaires.

Messages clefs

- Le début de la maladie est souvent précoce (entre 15 et 25 ans).
- Devant tout épisode dépressif, il est recommandé de rechercher des arguments en faveur d'un trouble bipolaire. Il est important de différencier les troubles bipolaires d'un épisode dépressif caractérisé isolé ou récurrent car le traitement et la prise en charge ne sont pas les mêmes.
- Pour le diagnostic, la rupture avec le fonctionnement psychique antérieur et le caractère épisodique des troubles sont deux notions importantes.
- L'évaluation du risque suicidaire est primordiale.
- Devant une tentative de suicide chez un adolescent ou un adulte jeune, il est nécessaire de rechercher un trouble bipolaire.
- Les adolescents souffrant d'un épisode dépressif et présentant un antécédent familial de trouble bipolaire requièrent une surveillance accrue.
- Le patient pour lequel un diagnostic de trouble bipolaire est envisagé doit être adressé à un psychiatre pour confirmer le diagnostic, suivre le patient et/ou donner un avis spécialisé en collaboration avec le médecin traitant et avec la famille et les proches. Une collaboration étroite entre le psychiatre et le médecin traitant est indispensable.
- Envisager l'hospitalisation pour les patients présentant un épisode maniaque ou mixte ou pour tout épisode présentant des critères de sévérité.

Date de validation
juin 2015

La HAS

- › Commission des stratégies de prise en charge
- › Commission des pratiques et des parcours
- › Méthodes d'élaboration des recommandations de bonne pratique
- › Méthode d'élaboration des Protocoles nationaux de diagnostic et de soins (PNDS)

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Service des bonnes pratiques professionnelles
› Nous contacter

TAGS

- › Dépistage, prévention
- › Dépression et troubles de l'humeur

Bonne pratique - Dernières publications

- › Syndrome de Cohen

- › Site de l'accréditation des médecins
- › Productions et enseignements
- › Chiffres-clés

Outils, Guides & Méthodes

- › Développement Professionnel Continu (DPC)
- › Protocoles pluri-professionnels
- › Education Thérapeutique du patient
- › Examen classant National

Documents

- › Patient avec un trouble bipolaire - Fiche mémo (613,13 Ko) Écouter
- › Patient avec un trouble bipolaire - Rapport d'élaboration (649,47 Ko) Écouter

› Documents complémentaires

> La fiche mémo au format web

Article > Patient avec un trouble bipolaire : repérage et prise en charge initiale en premier recours

Mis en ligne le 06 oct. 2015

En savoir +

- › Décision n°2015.0144/DC/SBPP du 3 juin 2015 du collège de la Haute Autorité de santé portant adoption de la fiche mémo « Patient avec un trouble bipolaire : repérage et prise en charge initiale en premier recours »
- › Programme "psychiatrie et santé mentale" de la HAS
- › Trouble bipolaire - Vidéos - interview du Dr Philippe Guillou, médecin généraliste
- › Infographie - Qu'est-ce que le trouble bipolaire

- › ALD n°16 - Maladie de Parkinson
- › ALD n°14 - Insuffisance respiratoire chronique grave secondaire à un asthme
- › ALD n° 14 - Insuffisance respiratoire chronique grave de l'adulte secondaire à une bronchopneumopathie chronique obstructive (BPCO)
- › Épisode dépressif caractérisé de l'adulte : prise en charge en premier recours

VIDÉO

Pourquoi le trouble bipolaire est-il difficile à diagnostiquer ?
13/02/2015

© 2015 Haute Autorité de santé

While NIMH largely steered away from dramatism in its performance, suicide or the risk thereof comes to figure as an important twist in the plot HAS develops about bipolar disorder, raising the stakes and adding urgency to the need to correctly diagnose and manage this condition. The ability to assess the risk of suicide is this way transformed into one of the competencies that medical professionals involved in the management of this condition need to master. To assist them in this process, HAS engages in the construction of new categories, as it puts forward a specific assessment of a suicidal crisis — low, medium, high — and highlights social isolation as an indicator of medium or high level.

As a public agency, HAS seems to be particularly sensitive to the ideal of public accountability, given that the other main character on this stage is a report providing an elaborate description of the steps and negotiations taken to develop the memo card (3). This document reveals the credentials of the team of experts involved, testifies to the depth and breadth of the literature consulted, and reveals the numerous actors that were consulted before the final product — the memo card — was publicly made available: different types of medical professionals, several patient organizations, non-governmental organizations, etc. It also casts light on some of the alliances HAS forged in order to develop the memo card, while the fragments from the various reviews give the audience the impression that they know what the most heated debates focused upon, and who was most and least in favor of the memo card. Whereas such information was absent from the online platform of NIMH, possibly in order to avoid any liability and potential causes for litigation, the audience of HAS has thus the opportunity to understand the tremendous scientific and diplomatic effort involved in such an undertaking, and seems to be invited to appreciate this institution's inclusive character. This latter aspect contributes to further legitimize this instrument, as representatives of most stakeholders have reviewed it. By placing on the frontstage a document which one generally expects to find relegated to the backstage, HAS seeks to present itself in a positive light, as an authoritative, but at the same time reliable, transparent, democratic institution.

This might suggest a certain degree of awareness on this institution's behalf regarding the current critical climate towards psychiatry, the ongoing struggles between different types of medical professionals, and the French population's penchant for distrust towards governmental institutions. It also reveals that the socio-political context in which such public agencies operate importantly shapes the distribution of elements between the front- and backstage. This becomes all the more obvious when comparing HAS' efforts at transparency and public accountability with NIMH's apparent unawareness of the diversity of opinions surrounding mental health and of the critical views on the abilities and interests of medical professionals. Nevertheless, whereas HAS' efforts are laudable, one cannot help but wonder what elements have been relegated to the backstage through this seemingly transparent approach or where the actual backstage is now to be found. While the data available for this study cannot provide a satisfactory answer in this respect, the analysis suggests that institutions engage in complex processes of front- and backstaging online, whereby their online platforms come to resemble Victorian cabinets, hosting numerous plays within what appears to be just one.

2.5.4 HAS' role in the reform of the French national mental health system

HAS has made ample use of the fact that the architecture of online platforms has rendered the existence of multiple simultaneous frontstages possible. The findings reveal that over the years this institution has developed three frontstages where it puts up different, but related performances about bipolar disorder: the memo card with recommended practices for the diagnosis and management of bipolar disorder (2015) discussed above; a press communication in HAS' online magazine (2015); and the guide for bipolar disorder as a chronic condition (2016) (Fig. 2.3). Thus, for HAS' overall performance to succeed and to be persuasive, it has to achieve coherence and coordination at two levels: at the micro level, constituted by each individual stage, where multiple characters interact in front of audiences with specific interests, and at the macro level, where all the perspectives on bipolar disorder it has shared on the different online pages of its platform need to be aligned. This means that the scientific facts and the medical advice that HAS provides on these three stages were carefully selected and have sufficient scientific credibility, so as to not jeopardize the success of its overall expertise enactment. Furthermore, the multiple stages also reveal that the performance on bipolar disorder that HAS puts up has increased in complexity over the years, as more information has been made available on the different pages of its platform.

If we consider the information provided on the first two stages (Fig. 2.2 and 2.3) and its intended audience, it becomes obvious that HAS seeks to assist in the reform of the French mental healthcare system. As mentioned in the previous chapter, the reforms involve plans for a substantial decrease in the number of psychiatrists, and proper care can only continue to be provided if other medical professionals are willing to take up some of the tasks the former fulfilled. General practitioners (GPs) are among those who will take over some of the responsibilities previously bestowed upon psychiatrists. To better prepare the GPs, HAS provides them with guidelines regarding various tasks and competencies, from the correct diagnosis of bipolar disorder, to familiarity with the new distribution of duties and responsibilities between GPs, psychiatrists, other mental healthcare professionals and patients (see Fig. 2.2 and 2.3), to indications of the types of therapeutic interventions that are officially reimbursed (see Fig. 2.3). To succeed in these efforts, HAS appears to have paid particular attention to the way in which it structured its performance and to the sign equipment it used.

Figure 2.3 Images of the upper and lower part of HAS' online page dedicated to bipolar disorder as a chronic condition

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- Méthode d'élaboration des Protocoles nationaux de diagnostic et de soins (PNDS)

Accréditation & Certification

Écouter

Guide maladie chronique

ALD n° 23 - Troubles bipolaires

Date de validation
novembre 2016

- Les actes et prestations sont un document de référence pour le médecin traitant pour l'élaboration du protocole de soins en vue de l'admission ou le renouvellement en ALD
- Le guide à l'attention des patients, destiné à être remis par le médecin traitant, vise à soutenir le dialogue médecin-malade

Documents

- ALD n° 23 - Actes et prestations sur les troubles bipolaires - Actualisation novembre 2016 (609,65 Ko) Écouter
- ALD n° 23 - Guide patient : la prise en charge d'un trouble bipolaire (50,97 Ko) Écouter

Mis en ligne le 09 déc. 2016

En savoir +

- Décision n°2016.0209/DC/SA3P du 30 novembre 2016 du collège de la Haute Autorité de santé adoptant le document intitulé « Actes et prestations – Affection de longue durée : Troubles bipolaires »

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Le Webzine de la HAS

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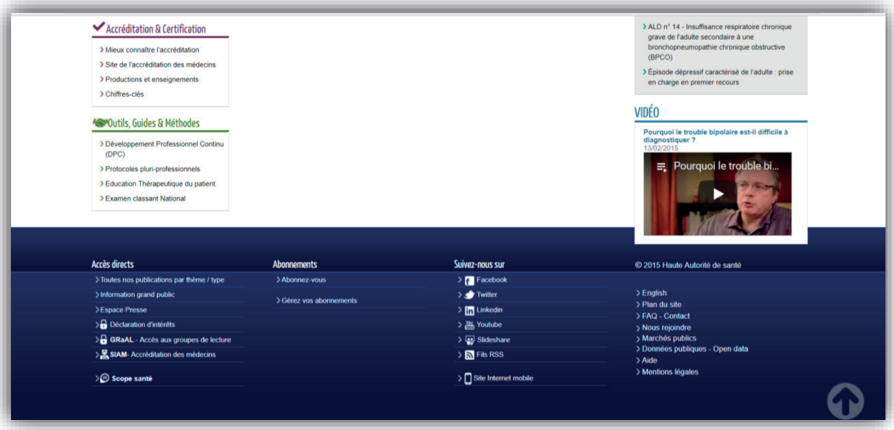
- Dépression et troubles de l'humeur

Bonne pratique - Dernières publications

- Syndrome de Cohen
- ALD n°13 - Maladie coronarienne
- ALD n°16 - Maladie de Parkinson
- ALD n°14 - Insuffisance respiratoire chronique grave secondaire à un asthme
- ALD n° 14 - Insuffisance respiratoire chronique grave de l'adulte secondaire à une



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- Education Thérapeutique du patient
- Examen classant National

- ALD n° 14 - Insuffisance respiratoire chronique grave de l'adulte secondaire à une bronchopneumopathie chronique obstructive (BPCO)
- Épisode dépressif caractérisé de l'adulte : prise en charge en premier recours

VIDÉO

Pourquoi le trouble bipolaire est-il difficile à diagnostiquer ?
13/02/2015

Pourquoi le trouble bi...

Accès directs

- Toutes nos publications par thème / type
- Information grand public
- Espace Presse
- Déclaration d'intérêts
- **GRaAL** - Accès aux groupes de lecture
- **SIAM**- Accréditation des médecins
- **Scope santé**

Abonnements

- Abonnez-vous
- Gérez vos abonnements

Suivez-nous sur

- Facebook
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- Youtube
- Slideshare
- Fils RSS
- Site Internet mobile

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- English
- Plan du site
- FAQ - Contact
- Nous rejoindre
- Marchés publics
- Données publiques - Open data
- Aide
- Mentions légales

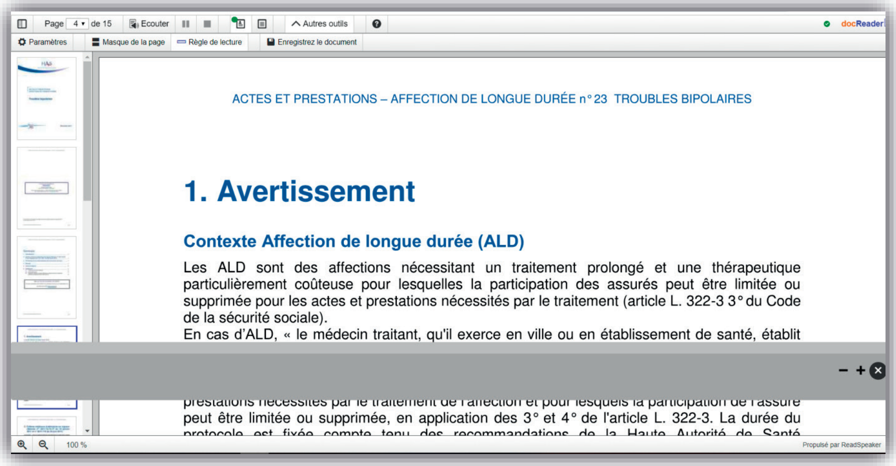
As already mentioned, noninteractive online platforms, where mainly static content is provided and where the capacities for social reactions and interactions are limited, can be seen as rather conservative options, considering the great diversity of dynamic and interactive platforms currently available. They also seem rather ill-fitting for an agency that has a mandate to evaluate online platforms and decide upon their quality. Since the rapidly changing online environment does little to suggest that a return to static websites is likely, it would be more constructive for such official bodies to experiment and acquire deeper insights onto the ways in which reliable knowledge can be put forward in interactive formats. Yet, as Figures 2.2 and 2.3 reveal, HAS has opted to dress its main characters in the simple and conservative outfit of portable document format (pdf) files, and to wrap some of its side actors in the equally conservative suit of digital text.

Whereas both HAS and NIMH use digital text in their performances, they ascribe it different connotations. Thus, HAS only uses digital text for the side actors, thereby making the identification of the main actors easier. Unlike HAS, NIMH has refrained from providing pdf files and used, instead, visual markers and aspects of the architectural design of its platform to signal to its readers the most important information. This distinction may also be due to the different audiences these two governmental agencies target, as the analysis of NIMH's performance showed that it focused primarily on providing information to the general public, whereas HAS seeks to educate medical professionals. Consequently, HAS' performance is organized as a series of monologues, with each individual character taking his/her turn to play his/her part. This way, the audience can focus upon what each character has to say without any interruptions, contradictions, or divagations. As pdf files, the costumes of the main characters are hard and rather impenetrable. By wearing them, each part these actors have to say, every insight and practical advice about bipolar disorder that they provide acquires greater stability and a certain degree of immutability, which befit scientific facts. In the official and reliable atmosphere created by the stage decorum and the rigidity of these costumes, the claims conveyed by the actors acquire greater credibility and authority. This impression is further guaranteed by this conservative attire, which prevents enthusiastic or disgruntled audiences to modify its cut, to change its colors or to give it a different twist by adding new accessories to it. Thus, the combination of short online text and pdf files might have been preferred as it allows HAS to better align each part, and to maintain greater control upon the performance it puts up by limiting the audience's involvement. At the same time, the choice for a noninteractive platform may be due to HAS' intention to keep under check the internet's penchant for exaggeration and fabrication, to guarantee the quality of the information it makes available and to increase its usefulness.

This choice of costumes for the main characters seems also to confirm the idea that HAS has taken up the task to successfully contribute to the reform of the mental healthcare system in France, as it has selected formats which lend themselves easily for educational purposes. pdf files present numerous advantages in this sense, as they allow for relevant information to be highlighted and easier identified, and they enable users to add their own thoughts and ideas in the form of comments and notes. At the same time, they can be accessed from a variety of devices. While such attire allows HAS to fulfill the WCAG 2.0 accessibility recommendations, this format is also better equipped to be consumed by careful and goal-oriented readers, such as treating doctors, who need to act quickly and who require stability and coherence in their practices.

The treating doctors' projected increase in workload and the need for efficiency may have prompted HAS to use another affordance in designing the costume of its actors, the audio file. While it is not made obvious, this format can also be used in a combined way, as it allows users to choose whether they want to listen or to read, and, in case they choose to listen, whether they want to see the text clearly or not. Moreover, users can also use a "reading ruler" in order to read in a more focused way or to make sure they follow the pace of the speaker, if they choose to both read and listen (see Fig. 2.4). This way, HAS allows treating doctors to choose a format which is better aligned with their personal studying or memorizing techniques, as some may focus better using visual means, others may prefer audio props, while yet others may find a combination thereof most helpful. Furthermore, while the typed text requires the user to focus mainly upon it, the audio format allows doctors to listen to HAS's advice also when engaged in other activities, such as walking or driving. While HAS is rather conservative in choosing the pdf format as the costume for its main actors, the additional audio option is not often encountered on the online platforms of other institutions and was absent from NIMH's description of bipolar disorder. Its use increases the likelihood that HAS carefully selects from among the various online tools available those which would be most helpful for its audience, by considering technologies and forms of accessing information with which the latter will already be very familiar. At the same time, such selection is also made in order to support the performance the characters engage in about bipolar disorder.

Figure 2.4 Image of the affordances —audio & reading ruler —of a .pdf file provided by HAS



ACTES ET PRESTATIONS – AFFECTION DE LONGUE DURÉE n° 23 TROUBLES BIPOLAIRES

1. Avertissement

Contexte Affection de longue durée (ALD)

Les ALD sont des affections nécessitant un traitement prolongé et une thérapeutique particulièrement coûteuse pour lesquelles la participation des assurés peut être limitée ou supprimée pour les actes et prestations nécessités par le traitement (article L. 322-3 3° du Code de la sécurité sociale).

En cas d'ALD, « le médecin traitant, qu'il exerce en ville ou en établissement de santé, établit

peut être limitée ou supprimée, en application des 3° et 4° de l'article L. 322-3. La durée du

As the distribution of roles and the choice of decorum indicates, HAS stages its performance on bipolar disorder as a rather idyllic world, where the best results can be achieved when treating doctors corroborate their treatment decisions with legal provisions regarding the insurance and reimbursement of medical care and when they provide their patients with documentation meant "to support the dialogue" between them. Given the currently fraught relations between different types of mental health professionals in France, this approach may have been taken in order to provide an example for its medical audiences to follow, as an attempt to achieve not only informational, but also behavioral changes. This element further confirms the idea that HAS seeks to ensure that the reform of the French mental healthcare system takes place successfully. Such an ambitious performance requires, however, careful preparation and coordination and the avoidance, in as far as possible, of any spontaneous elements. These considerations may have therefore informed HAS' choice of costume for its characters as well as the way in which it organized the reverberations of several plot twists across different regions of its three stages.

2.6 Discussion

This chapter has studied the performative techniques through which two highly influential institutions enact expertise about bipolar disorder online, in a context in which official bodies are required to make their insights available via the internet, but face important challenges to their authority, and need to respect specific technical provisions. To answer this research question, an innovative method has been developed by combining Goffman's (1959/1990) dramaturgical perspective and insights acquired from its application in the study of scientific authority (Hilgartner, 2000) with the suggestion that this approach may be amenable to phenomena involving digital technologies (Hafermalz et al, 2016). This method has allowed various digital objects and technologies to be approached as agents fulfilling different roles and functions in the performance NIMH and HAS put up on their online platforms: as main characters, costumes, stage decorum, etc. It has also focused the analysis on the ways in which seemingly disparate elements —aesthetic, functional, content-related— were combined to put forward specific perspectives on bipolar disorder for particular audiences. Since successful performances depend on the ability to render certain things visible while concealing others, this method has further highlighted that multiple front and back stages need to be considered online, depending not only on the ways in which information is organized and structured on the platform, but also on whether and how it can be archived and preserved (Rogers, 2013). At the same time, the use of this approach has implications for how the type of online platform that NIMH and HAS have selected is understood. According to Goffman (1959/1990), the success of a performance depends not only on the team's competence to convincingly put up a certain impression of reality, but also on its ability to prevent the audience from mistaking or misunderstanding the intended meaning of its performance. From this point of view, NIMH's and HAS' choice of noninteractive platforms may be seen as an attempt to restrict the audience's ability to challenge the versions of bipolar disorder they put forward.

The analysis shows that both NIMH and HAS enact expertise about bipolar disorder in a similar way, by re-framing the meaning of this condition through the provision of specific information and the development of new categories which are sustained by the performances they successfully put up on their online platforms. In so doing, NIMH and HAS are not enthusiastic users of the internet, exploring its full potential and experimenting with the latest online technologies. Instead, they opt for noninteractive online platforms which are reminiscent of the web 1.0 era, with static content and limited interactivity. These platforms are appropriate when the main goal is the provision of information in ways which make it accessible to as many people as possible, but they do not allow the audience to react to it in publicly accessible ways. Nor do they provide many opportunities to fulfill these institutions' educational goals in more appealing and less traditional fashions, such as through the use of dynamic, multimodal or gamified elements. The online platforms of NIMH and HAS are therefore rather conservative options, but they enable these institutions to put forward the currently available knowledge on bipolar disorder as stable and reliable.

The findings reveal that both NIMH and HAS shape their performance on bipolar disorder in view of particular audiences and their informational needs. While NIMH provides simple and general insights to educate people who may lack any knowledge on bipolar disorder, HAS puts up well-structured and easily accessible information to help medical professionals, in particular GPs, in their daily practice. While the ways in which the information is shaped depends on the audience these institutions target, the visual design of their platforms and most of the online affordances they use help readers better find their way on these websites. Perhaps more importantly, they also serve to reiterate the scientific character and authority both institutions enjoy offline. Thus, while the accessibility commitment may present important challenges for institutions which aim to share mental health-related information online, it is also a means through which such institutions can acquire further legitimacy. Moreover, the accessibility guidelines may also be used as a convenient excuse for such stakeholders to engage with the online technologies they feel more comfortable about or which they can better use in order to put forward a desired public image.

One of the specificities of the internet is that it allows such institutions to put up multiple performances on related stages. This way, the audience can easily find and quickly access only the information they are interested in. While achieving coordination among multiple stages is no small feat, when done successfully such an approach can also help heighten the credibility and scientific character of the insights provided, through repeated self-citation and heightened exposure of the audiences to the same claims. From this point of view, the findings presented here confirm Latour's (1987) views on the development of scientific facts, despite the different media studied.

These findings have been colored by a specific normative perspective, which sees noninteractive online platforms as rather conservative, whereas interactive online platforms are perceived as more dynamic and amenable to varied purposes. Choosing for an interactive online platform can be problematic for official institutions, because of the inherently generative character of such platforms, where users can engage with the content made available in ways that may lead to interpretations and evaluations of varying quality, and may put forward suggestions that may be detrimental to others. It is regrettable, however, that neither NIMH nor HAS has tried to reach a balance between control over the platform and more distributed forms of agency, where users would have had some possibility to contribute, if not to the production, then, at least, to the evaluation of the insights these institutions shared. Instead, both have chosen to use rather conservative online technologies in their performances. The need to educate people of different socio-economic levels and to render insights available to those with disabilities is not a sufficient explanation for this choice, since online technologies with more open and flexible affordances exist, which can be accessed also from affordable devices, and which may promote more effective and lasting engagements with the information provided. NIMH and HAS' approach is in stark contrast to initiatives developed in recent years in fields ranging from business and marketing to education (Dicheva et al, 2015), personalized health (McCallum, 2012) and e-health (Sardi et al, 2017). In these fields, diverse, interactive, gamified elements are integrated to digital technologies and applications to steer the behaviors of users in specific ways. Such initiatives are also problematic, however, as they are fueled by visions of the individual as homo economicus, mainly interested in furthering one's personal interest based on rational calculations. They thus neglect, among others, the important role social ties, traditions, norms and values play in shaping one's behavior (Swierstra, 2016). Furthermore, they may also be reproached, to a certain degree, for trivializing serious matters and infantilizing users.

While these reservations are important to bear in mind, the use of interactive online platforms endowed with a diverse array of affordances may help people acquire a better and longer-lasting understanding of complex issues. At the same time, the availability of multiple options from which people can choose how they want to engage with the information provided may further public engagement. Since HAS has the authority to certify health-related online platforms in France, their online use of the internet is all the more important, as it might serve as an example for other institutions and governmental agencies. From this point of view, its conservative and rather apprehensive approach to the internet does little to encourage other stakeholders to share their insights online in more democratic and interactive ways. Comparing the websites of these two institutions with the online platforms of patient associations and mental health advocates, it appears that differences among stakeholders in public/private legal status and authority are enacted online through rather strict divisions between interactive and state-of-the-art online technologies and noninteractive, conservative online tools.

In terms of the content they made available online, both NIMH and HAS sought to redefine bipolar disorder in view of achieving particular means. NIMH sought to safely position it in the brain, thereby heightening the scientific approach to the diagnosis and treatment of bipolar disorder and also contributing to the legitimation of a research agenda focusing on the neurosciences. How such reconceptualization would affect different types of mental health professionals, such as psychologists or social workers, represent important aspects, which were, however, relegated to the backstage. Given the delay in correctly diagnosing bipolar disorder, HAS sought to put additional pressure on treating doctors by advancing an understanding of bipolar disorder as degenerative. At the same time, it also reframed it as a highly suicidogenic condition. Thus, even though they used similar performative techniques, these two institutions chose to redefine bipolar disorder in different ways. Such differences may be informed by the national characteristics or by the priorities sketched out within their respective mental healthcare systems. For instance, the higher suicide rate in France (14.3%) as compared to the U.S. (13.1%) (OECD, 2015) may be the reason why HAS has chosen to enact expertise about bipolar disorder by developing categories of suicide risk while putting up a perspective of this condition as highly suicidal. Furthermore, NIMH's definition of bipolar disorder as a neurological condition is understandable in the American context, where the biomedical model is dominant and where Congress has been increasingly approving the allocation of funds in areas of research which can provide hard evidence and which can lead to findings that are easier to render profitable. Furthermore, while politics play an important role in the functioning and orientation of both agencies, they both successfully managed to relegate it to the backstage, presenting an image of governmental bodies moved by the sole purpose of furthering science and improving the treatment and provision of care to people diagnosed with bipolar disorder.

Both NIMH and HAS took up the incentive to share knowledge about bipolar disorder online, but they did so in ways which suggest that they are either oblivious or unwilling to substantially engage with the fact that their authority is questionable and questioned, and they need to convince as experts if they want to succeed in educating their public. The analysis shows that they enact expertise by simply updating the information on their online platforms. Yet whereas HAS has made some efforts towards acknowledging its public accountability, NIMH largely continues to issue pronouncements in a technocratic fashion. While this might be a defense mechanism, a way to steer off the public critical climate, it renders these agencies less effective in the convincing provision of insights. Through such practices, they also do not live up to the image they seek to perform online as supporters of public engagement. Whereas this chapter has described how influential governmental agencies enact expertise about bipolar disorder by putting up specific performances online, the next chapter will show that particular types of interactive online platforms —blogs and fora— allow people diagnosed with bipolar disorder to engage in more substantial ways in processes of knowledge production and evaluation about treatment.

Chapter 3

Tactical re-appraisals and digitally-informed hypotheses about the effectiveness of treatment for bipolar disorder

CHAPTER 3

3 TACTICAL RE-APPRAISALS AND DIGITALLY-INFORMED HYPOTHESES ABOUT THE EFFECTIVENESS OF TREATMENT FOR BIPOLAR DISORDER[8]

While patient engagement in mental healthcare has a long tradition, as already mentioned in the first chapter of this dissertation, since the late 1980s a series of factors has led to a growing responsibilization of people in regard to their health (Petersen & Lupton, 1996) and has stimulated them to contribute to the production of knowledge. The internet has played an important role in such developments (Wyatt et al, 2013), as it has allowed people diagnosed to enroll in medical studies more easily, to engage in practices of self-monitoring and -experimentation, and to exchange information with more people with the same diagnosis than was previously possible. Yet, while patient engagement is welcomed and encouraged, what exactly is meant by it, what patients are expected to contribute, and what the limits to such contributions are or should be remain debatable (Lupton, 2018; Adams, 2011).

These issues are exacerbated online by the variety and specificity characterizing both mental health conditions and online platforms, which shape the content and character of interactions. More research is needed to map out what patients contribute online, and to understand how such contributions are contextually shaped. Whereas the previous chapter showed how official institutions enacted expertise about bipolar disorder, the current one marks the turn in this dissertation towards the various activities undertaken by people diagnosed with bipolar disorder and the different types of expertise they enact online. We remain close to medical perspectives on bipolar disorder, however, as this chapter studies how people diagnosed with bipolar disorder use blogs and fora to share their treatment experiences. Using de Certeau's theory (1988) of creative tactics in everyday life, this chapter argues that through their online interactions, they move beyond the enactment of lay expertise and collectively generate what I[9] call "digitally-

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[8] The materials used in this chapter from the blog *Bipolar Burble* have been included in an article titled "Bipolar patients and creative online practices: sharing experiences of controversial treatments", that was published in the journal *Health*, https://doi.org/10.1177/1363459319838315.

[9] I was inspired to use the term "hypothesis" by some French online contributors, who used this notion to describe a suggestion regarding the effects of certain environmental factors on treatment effectiveness put forward by other people diagnosed with bipolar disorder on the forum *Le Forum des Bipotes*.

informed hypotheses" in areas where the currently available medical knowledge on the effects and side-effects of medications is insufficient.

3.1 Problematizing patient engagement

People diagnosed with mental conditions have assumed a growing role in the production of knowledge, as the provision of treatments and caring practices has shifted in the context of de-institutionalization from medical environments to more private and non-clinical settings, such as homes and community centers. As such, patient engagement in mental healthcare has developed under various forms, ranging from club houses, self-help and support groups (McLean, 2003), focusing on the societal reintegration of people diagnosed with mental conditions, to social movements, such as the psychiatric consumer/survivor/ex-patient movement, whose members "attempt to shape treatment to respond to their own needs" (Morrison, 2013: ix). Since the early 1990s, people diagnosed have also participated in the provision of psychiatric care, as paid or voluntary case managers, facilitators or peer support providers (Davidson et al, 2006). As such, they have been involved in numerous ways not only in care but also in the production of knowledge about treatment.

More recently, patient engagement has been encouraged through top-down and grassroots initiatives meant to improve the provision of mental healthcare and to render it more cost-efficient. Social media and digital technologies have played an important role in these developments, as they have provided new avenues for patient engagement, which have been both celebrated and critiqued. In the early days of the public internet, some commentators expected this medium to empower patients, contributing to the re-appreciation of lay expertise (Hardey, 1999). Others have criticized digital technologies as a means for creating free labor, as a neoliberal practice of outsourcing tasks and responsibilities onto individuals while decreasing social provisions (Rose, 2018; Thomas, 2016). Most medical sociologists and media scholars agree, however, that digital technologies have contributed to more active conceptualizations of the role of patients (Felt, 2015). The personal experiences of (pre)patients have become all the more important (Prainsack, 2018), as the adoption of Big Data analytics in healthcare and the drive towards precision medicine make highly diverse data necessary, including next to traditionally "medical" markers, information such as credit card purchases and social media interactions (Weber et al, 2014). This has contributed to new perspectives on what counts as evidence (Hogle, 2016) and to intensified calls for individuals to engage in self-monitoring practices and to contribute information.

3.1.1 Theoretical approaches to patient engagement

Attempts to determine the knowledge of patients have a long history (Segall & Roberts, 1980), and more recently patients' use of online platforms has served to further problematize their relations with medical professionals and to nourish ongoing discussions about the type and relevance of the knowledge each party contributes (Versteeg et al, 2018). While medical knowledge is generally seen as relying upon scientific and clinical insights, patients are often ascribed experiential knowledge, that is, "truth learned from personal experience with a phenomenon rather than truth acquired through discursive reasoning, observations, or reflection on information provided by others" (Borkman, 1976:446). Arksey (1994:455) proposed the notion of "lay expertise" to acknowledge the substantial technical knowledge people diagnosed could acquire informally and to argue that it could enable them "to reverse the usual doctor-patient relationship and instead stimulate a two-way learning process". Epstein further developed these insights, showing how some AIDS activists had "learned the language and culture of medical science" (1995:17), and were thereby able to engage in and change medical research and clinical practices. Epstein's findings showed that the acquisition of such knowledge alienated those who had acquired it from the general community of AIDS activists, leading him to distinguish between "lay experts" and the "lay lay". Closely related to "lay experts" is the notion of interactional expertise, which Collins and colleagues (2017:765) recently refined to denote "fluency in the spoken language associated with a practice", acquired through immersion in that field. Anxious to safeguard the substantial character of expertise, they see interactional expertise as the property of specific individuals and groups. While I shall return to this concept and work with it extensively in the following chapter, it is less useful for a study of online interactions between rapidly changing participants, whose medical knowledge is acquired through reading and appointments with medical professionals, rather than through immersion.

More appropriate for studying online exchanges involving many participants is the perspective provided by Wilcox, who argues that lay expertise should be understood as "collective knowledge that may be widely available yet is still unevenly socially distributed" (2010:45). This is reinforced by studies of health-related online behaviors that have shown that "[s]ocial media platforms facilitate the sharing of health information between users and the co-production of new knowledge that is shaped by personal experience" (Sosnowy, 2014:316). In the past, patient associations have collected and processed the experiences of numerous individuals diagnosed to transform them into collective knowledge. I argue that such practices are nowadays facilitated by blogs and fora. According to Tremayne (2007:vii), "[b]logs are distinguished from other websites in their dynamism, reverse chronological presentation and dominant use of the first person." Fora are "Internet locations in which people can read and post messages singly or in a developing 'thread'" (Antaki et al, 2006:114), and where these insights accumulate, turning the fora into rich discussion databases. This definition highlights an important distinction between blogs and fora, which may lead to different power relations and to different dynamics between online contributors. While on blogs, people diagnosed mainly contribute as reactions to the posts shared by the blog author(s), on fora, even though threads can also be initiated by the forum owner/administrator, they are largely developed by individual users, who want to receive advice on a particular issue. Nevertheless, both blogs and fora may enable collective processes of knowledge production by bringing together people with the same diagnosis but endowed with different types of knowledge, skills, and resources, by facilitating their dialogue, and by preserving their exchanges. Blogs and fora are important to study, since "[h]ealth issues are today often negotiated in parallel with professionals in institutional settings like hospitals and among peers in activities taking place online" (Bellander & Landqvist, 2018:1).

3.1.2 Lay expertise and bipolar disorder

Lay expertise is often articulated in situations when scientific knowledge is lacking, when it has not yet stabilized or when issues are too complex to be solved using only one type of knowledge (Baillergeau & Duyvendak, 2016). This makes its study in relation to bipolar disorder relevant. As already mentioned in chapter 1, while its causes are not precisely known (Frey et al, 2013), bipolar disorder is thought to be determined by a combination of genetic, neurological and environmental factors. Treatment is prescribed in a rather formulaic fashion, and there is still limited understanding of how the prescribed medicines work. Finding an effective treatment regimen for any individual patient may take several months or years. In the case of bipolar disorder, therefore, there is a significant amount of space for people diagnosed to contribute to knowledge, making it an interesting site to study patient engagement and expertise enactment. According to Britten and Maguire (2016), while medical professionals appreciate patient engagement in various aspects of clinical practice and research, patients' experiences about treatment have not been sufficiently acknowledged. Furthermore, whereas new drugs prescribed for mental conditions are assessed based on short clinical trials (involving typically six weeks of exposure), many of them are used as maintenance treatment. This means that "the effects of these drugs as used in practice are not known" (Frank et al, 2005: 292) and "decisions about payment, inclusion, placement in formularies and clinical management are usually not informed by data on long-term clinical or economic consequences" (ibid.) At the same time, whereas pharmaceutical companies have used new approaches, such as direct-to-consumer advertising (DTCA), to promote their products, the degree of involvement of people diagnosed with mental conditions in pharmaceutic regulatory processes remains limited (Healy, 2008). What further complicates matters in the field of mental health is that treatment compliance and adherence remain problematic, leading to important tensions between medical professionals and people diagnosed. Yet, these are all aspects about which people diagnosed with bipolar disorder may be very insightful, so the internet may provide a welcoming space for those among them who want to share their treatment experiences and contribute to the development of new knowledge.

3.1.3 Studying tactics online

Over the last decades, official institutions have emphasized the need to inform and consult the public about scientific findings and research agendas. This has contributed to the distribution of scientific information in numerous shapes and across different media. According to Epstein (1996:177), "debates about the safety and efficacy of treatments travel with particular ease between the pages of scientific publications, the mass media…" due to their highly politicized character and the different types of stakeholders involved. Since finding effective treatment is a priority for people diagnosed (Thompson et al, 2012), such debates no doubt reach them. Their response to such information may vary, as patient engagement does not occur in conditions of absolute autonomy or social control. Building upon Sharon (2015), I use de Certeau's (1988) theory of creative tactics in everyday life, as it allows me to study how people diagnosed with bipolar disorder take up elements of the dominant discourse regarding the effectiveness of medications, and transform them in their attempts to adjust treatment to their personal needs and preferences. De Certeau (1988: xix) defines tactics as

> a calculus which cannot count on a 'proper' (a spatial or institutional localization), nor thus on a borderline distinguishing the other as a visible totality. (...) A tactic insinuates itself into the other's place, fragmentarily, without taking it over in its entirety, without being able to keep it at a distance. (...) It must constantly manipulate events in order to turn them into 'opportunities'.

Tactics are therefore ingenious actions through which individuals seek to re-appropriate dominant representations by adapting them to their own needs, rules, and goals. While tactics represent creative actions, they should not be understood as intentional means through which individuals seek to resist the current health regime, but rather as actions emerging within a certain dominant order through which the space of this order is rendered more habitable, where habitability depends on individual circumstances. De Certeau illustrates this by invoking a person adapting a cooking recipe to the ingredients available or reading diagonally across the page when in a hurry or looking for specific information. Similarly, people diagnosed with bipolar disorder may be urged to educate themselves and to use online platforms in specific ways to better manage their condition. However, anthropological and STS studies (Harris et al, 2014) have shown that people respond in different ways to such exhortations and engage creatively with available technologies, depending on their goals and resources.

For instance, in a study on HIV/AIDS patients, Whyte (2005) has shown that patients "try out ideas" and come together to show the results of such self-experiments to improve their quality of life. Pols (2014) developed the concept of "patient knowledge", which is both practical and situated, consisting of knowing how and knowing-now. Patients acquire it in dialogue with each other, by combining medical knowledge with their own experiences and by tinkering with the various therapeutic devices they use to better manage their condition. Recently, Kingod (2018) has shown that patients diagnosed with chronic conditions co-construct knowledge, by exchanging information about their practical experiments on Facebook.

3.2 Methodology

Tactics, in de Certeau's framework, represent creative adaptations of dominant representations. Thus, I first sought to delineate the main characteristics of current medical knowledge on the treatment of bipolar disorder by consulting the literature. This involved an initial consultation of relevant sociological studies (Collin, 2015; Healy, 2008; Lakoff, 2005), followed by the review of 30 highly cited medical articles published between 2000-2016. The characteristics arrived at this way were further refined by reading the abstracts of 15 medical articles published between 2010-2018. The three characteristics identified, as further explained below, are *uncertainty, complexity, individualization*, and they guided the analysis of the online data.

Online data were gathered from one French and one American interactive platform. *Le Forum des Bipotes* (LFB) is a forum developed by a person diagnosed with bipolar disorder. LFB was founded in 2007 and functioned until 2014. While it is no longer active at the moment, it enjoyed great popularity and it is still maintained online as a source of information. *Bipolar Burble* is the personal blog of Natasha Tracy, who is diagnosed with bipolar disorder. She enjoys celebrity status in this world, as the blogs she has authored have repeatedly been listed among the top best blogs about bipolar disorder, and appear on the first page of results by search engines such as Google. In choosing these online platforms, I aimed to mimic the approach of regular users, and, using the Google index as an indicator of relevance, I limited the selection to the results provided on the first 30 pages. The selection was further refined by excluding multiple pointers to the same item, and by filtering out blogs and fora which were not in English and French, which had been established for less than one year at the moment when the selection took place (September 2014), which did not allow the information available on their platforms to be used for research purposes, and which had few contributors (<10). From these online platforms, I selected 30 entries which covered the treatment of bipolar disorder, broadly understood, and which had more than 30 comments each.

More specific information about the blog and forum entries used can be found under Appendix B.

In analyzing the data, I built upon insights from sociolinguistics (Blommaert, 2005), which highlight the action-oriented and power-laden character of language. An asset in itself, language is also a means to acquire other resources and to achieve specific goals, such as claiming a particular identity, displaying a certain type of expertise, distinguishing between different claims. While the intentions with which the contributors write their comments remain opaque, the subsequent reactions illustrate how other online participants have perceived these comments, whether they have treated them as truthful, valuable, similar or different to their own experiences. Using computer-mediated discourse analysis (Herring, 2012), I identified recurrent themes as well as variations in the personal accounts of people diagnosed with bipolar disorder, focusing on: (i) how they positioned themselves in relation to medical perspectives on treatment; (ii) how they sought to develop alternative accounts, and (iii) how they negotiated the development of new hypotheses about treatment effectiveness. I classified each contribution based on how the insights put forward related to the three characteristics of medical knowledge on the treatment of bipolar disorder mentioned earlier. I further distinguished between them based on how the contributors understood their condition and on their expectations regarding the effects and scope of treatment. Particular attention was paid to the means through which contributors sought to express the different types of knowledge they were endowed with, to orchestrate them, to manage inconsistencies, and to negotiate between different perspectives in their efforts to develop new digitally-informed hypotheses. Excerpts are therefore reproduced as they appeared online, with no spelling nor grammar corrections. French quotes were translated by me.

The data were collected from public blogs and fora with free access, where the contributions made indicated that the participants did not expect their interactions to have a private character (Bakardijeva & Feenberg, 2000). This is therefore in accordance with current ethical guidelines on online research (BPS, 2013). As I already mentioned in chapter 1, the contributors' usernames were not anonymized in order to acknowledge the relevance and labor involved in their reactions and out of consideration for the fact that they may have grown attached to these usernames and internalized them as part of their identity (Varis, 2016).

3.3 Findings

3.3.1 Three characteristics of medical knowledge on the treatment for bipolar disorder

Treatment effectiveness in regard to mental conditions continues to be difficult to assess and determine. According to de Leon (2012: 156),

> [p]sychiatry has a long history of trying to identify predictors of differential pharmacological response, but these attempts began before the evidence-based medicine (EBM) approach was born, were not deployed in the context of RCTs, and were not tested in RCTs. These attempts came from a different tradition, the mechanistic tradition…

In the mechanistic tradition, the effectiveness of psychiatric drugs is due to their action upon specific mechanisms in the brain. In the aftermath of the Human Genome Project, the rise of personalized and precision medicine has contributed to numerous attempts to identify genetic markers for bipolar disorder and the biomarkers that render some of the people diagnosed with it responsive to specific treatments. As "the rapid progress in the "-omics" fields makes the notion of evidence a moving target" (Khoury et al, 2008: 1606), nowadays different types of evidence can be produced in multiple, innovative ways, in different settings and involving different stakeholders (Collins & Varmus, 2015). Nevertheless, the studies undertaken thus far have only been mildly successful in providing clear insights on the effectiveness of treatments for bipolar disorder. Treatment for this condition focuses on mood stabilization and maintenance, and combines medications and psychotherapy. The prescription of treatment for bipolar disorder continues to take place in a context where there are difficulties in achieving clinical consensus regarding the best treatment options, whereas attempts to identify biomarkers to explain the heterogeneity of drug responses among patients have generally been unsuccessful. Based on the literature review I undertook, I argue that current medical knowledge about the treatment of bipolar disorder is characterized by *uncertainty, complexity, and individualization*.

Uncertainty is "characterized by self-awareness of incomplete knowledge about some aspect of the world" (Han, 2013:16). In the medical field, "[t]he evidence in which different uncertainties are manifest ranges from anecdotal clinical observations to data from randomized clinical trials." (ibid.) Uncertainty about the treatment of bipolar disorder is informed by methodological issues derived from important characteristics of this condition, such as the considerable heterogeneity in the definition and assessment of a mood episode, relapse (Young & Neham, 2006), and therapeutic response. While EBM has led to "an ever-increasing demand for standardization and improved quality in psychiatric treatment" (Geddes & Goodwin, 2001:191), there is still a lot of uncertainty regarding the mechanism of action of various drugs used for the treatment of bipolar disorder. For example, anticonvulsants were introduced in the treatment of bipolar disorder because of certain similarities between this condition and epilepsy, but the current understanding of their action mechanism remains superficial. While the use of any antidepressants in the treatment of bipolar disorder is controversial, studies have reported important variations in their efficacy and tolerability. Yet, there is limited understanding as to the causes of such heterogeneity. Uncertainty also exists in relation to side-effects, and this is the case even for substances which have been long prescribed in the treatment of bipolar disorder. For instance, reports on the degree to which long-term Lithium use may lead to renal failure or to congenital malformations, when taken during pregnancy, are ambiguous.

Uncertainty is sometimes due to a lack of clarity, but there are also situations when it is due to a gap in knowledge. Various treatment combinations are often prescribed in clinical practice in response to patients' needs, side-effects or other medications they take, while there are no study results available to confirm or discourage such practices. Another type of uncertainty is linked to patient behavior, particularly treatment adherence. For instance, even though Lithium is frequently prescribed and is considered to be highly effective for mood stabilization, it may prompt more frequent episodes if it is abruptly interrupted. This is another aspect that renders treatment effectiveness more difficult to define and assess. At the same time, it indicates that treatment decisions need to be based not only on the best available evidence regarding the effectiveness of particular medications, but have to consider treatment adherence and the elements which mostly influence it (Levin et al, 2016).

Complexity denotes the multiple factors which may play a role in the development of a disease and/ or in an organism's reactions to treatment and the awareness that changes in any of these factors may affect the others in unpredictable ways, while sometimes remaining themselves hard to foresee (Plsek and Greenhalgh, 2001). In the case of bipolar disorder, complexity is derived from the diverse causes of this condition and the multiplicity of factors involved in its therapeutic approach, which make it difficult to assess the effects of specific elements and interactions and to make informed decisions about treatment. Numerous findings show that the effects of various medications used in the treatment of bipolar disorder are influenced not only by the level of specific hormones and other bodily values, but are also importantly shaped by one's genetic (Craddock & Sklar, 2013) and hereditary make-up. For instance, only 30% of people diagnosed with bipolar disorder are responsive to Lithium and researchers have been able to develop a general molecular and functional profile of this group. While such responsiveness was thought to indicate a subtype of bipolar disorder, more recent insights suggest that Lithium responsiveness is linked with certain symptoms and is heritable (Tighe et al, 2011). Genetic insights indicating that bipolar disorder is not a discrete entity have further contributed to the complexity characterizing the search for treatment, guiding such endeavors across traditional diagnostic boundaries (Harrison et al, 2016). The environment in which one finds oneself provides another complicating dimension (Harrison et al, 2016). Factors such as climate, family situation, workplace stress and especially shift work, that disrupts night and day rhythms, also influence treatment effectiveness. Comorbidity further complicates current understandings on treatment effectiveness, as medicines prescribed for other conditions may interact with the bipolar disorder treatment, leading either to different effects altogether or to weaker or stronger effects than expected. The timing when particular interventions are used seems also to importantly determine treatment selection and effectiveness. Thus, different medical combinations are considered depending on the condition's developmental stage (Sachs, 2004) and on the age of the people diagnosed. For instance, studies suggest that the use of psychoeducation to prevent relapses is most effective during the first years after diagnosis, with much more modest effects when taken up later (Miziou et al, 2015). Furthermore, the effects of particular medications only become fully manifest after being taken for a long period of time without interruptions.

Individualization understood as individual variations in treatment response has recently come more and more to the attention of researchers (Bates, 2010), and constitutes a move away from "standard" approaches, where reactions to medications are studied among relatively large groups. While the hope is that at some point treatment response will be studied at the level of each person of interest, individualization currently denotes practices which focus on subgroups of increasingly smaller sizes, as distinctions are made at greater levels of specificity. From this perspective, attempts at determining treatment effectiveness in the field of mental health have also been strongly influenced by developments in the field of pharmacogenetics, as various studies have shown that determining a patient's genotype can help when deciding upon the prescription of specific antipsychotic drugs (Tanaka & Hisawa, 1999). At the same time, various studies have focused on how and why particular subgroups diagnosed with bipolar disorder react differently to specific substances, requiring higher or lower dosages for the intended effects. Insights from personalized medicine have led to a growing awareness that evidence about treatment effectiveness requires taking into account parameters such as dosage, form, frequency, etc., and that genetic, hereditary and environmental factors may trigger different reactions in different individuals (Hedgecoe & Martin, 2003). Developments in genetics have prompted medical researchers to hope that genetic loci playing a role in the development of bipolar disorder will be found, leading to the identification of biomarkers and to the development of more effective treatment pathways and targets (Squassina & Pisanu, 2013). There has also been a growing recognition that "an individual's unique life circumstances... influence disease susceptibility, phenotype, and response to treatment" (Ziegelstein, 2015: 888). Next to genetic or genomic markers, various personal categories, many of which are dynamic and change numerous times throughout the life of a particular individual (Naylor & Chen, 2010) have thus come to play a role in the development of knowledge about the treatment of bipolar disorder. This way, the evidence about treatment effectiveness has been expanded to include the "psychological, social, cultural, behavioral, and economic factors of each person" (Ziegelstein, 2015:888).

Such realizations are not restricted to the pages of academic publications, but reach people diagnosed with bipolar disorder. In what follows, I show that they do not simply take note of this state of affairs but seek to enrich medical knowledge by putting forward what I call "digitally-informed hypotheses" about the effects and side-effects of medications.

3.3.2 Engaging with medical knowledge about the treatment of bipolar disorder online

While on the blog studied, online contributors were reminded of the current level of medical knowledge about the treatment of bipolar disorder by the blog author, many threads on the forum were initiated by people who had already gained insights about particular events from their medical professionals or from other sources of information. Thus, some threads were initiated by people who were about to start taking a new medication or who felt that a change in their treatment was needed and wanted to learn more about the treatment experiences other people had received. There were also many online contributors who developed new threads in reaction to the launch on the French market of new medications for bipolar disorder. This was, for instance, the case with Seroquel/Xeroquel[10] and Cymbalta, which had already been on the market in the U.S. for a few years, before they were commercialized in France. Aware of their existence, some French online contributors confessed to having long waited for them to become available. In contrast, others were interested about their effects and side-effects, because they were not familiar with them. From this point of view, these online contributions constituted important repositories of information and of initial experiences with a medication for the readers who were interested in them, but who could not access the information available elsewhere due to language barriers, or who were specifically curious about the perspectives of French users. As such, these online contributions no doubt influenced the readers' perspectives upon these medications and their willingness to try them, which may indirectly also have affected the prescription practices of medical

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[10] Whereas Seroquel is one of the most known names under which Quetiapine has been marketed in the U.S., Xeroquel is the name under which it is known in France.

professionals in this country. Forum contributors and readers were further reminded of the uncertainty, complexity, and individualization characterizing medical perspectives on treatment by the forum administrator(s), who provided hyperlinks and shared excerpts from medical publications or fragments from his personal correspondence with psychiatrists.

Similarly, the blog author invoked the uncertainty, complexity, and individualization characterizing this area in her posts and often made these aspects more vivid by combining them with lived experiences and third-party accounts. Tracy took up the role of mediator between medical professionals and people diagnosed, providing the latter with recent perspectives on bipolar disorder treatment. She also initiated discussions to challenge perspectives and practices which she found were popular among people diagnosed, but she thought were ultimately detrimental to their well-being and ran counter to medical views. Both on the blog and forum, the interaction occurred at two levels: as a dialogue initiated by the author or by a forum contributor, to which online contributors reacted directly through comments; and as a conversation initiated through the comment of an online contributor to the blog post or to a forum comment and developed through subsequent reactions to that specific comment. The behavior of online contributors was overseen and guided by the blog author and by the forum administrator(s), respectively. For instance, Tracy set in place specific rules regarding the content that could be shared on her blog, and the comments were reviewed before they became visible online. On the forum, the administrator tried to help people put the online insights provided into context, by asking online contributors to share personal information about themselves on a different thread.

The design of the blog and forum and their affordances affected how information accumulated, how it could be accessed and retrieved. For instance, in the past, interested readers would have had to collect and aggregate information from multiple printed publications to compare how people diagnosed reacted to medications. They would have had to visit archives to gain access to issues published in different years, would have needed a lot of physical space to store such materials, and would have arguably had a harder time finding so many different personal insights. Such practices were rendered easier on the blog, as the information provided in reaction to one post could be found in a single location, even though it spanned years and was provided by numerous contributors. The administrator played an active role in rendering the forum into a well-structured repository of insights, as he turned threads initiated by new comers into comments under existing threads, that were dedicated to the same issues. By bringing all information pertaining to a specific medication or to a certain side-effect thereof in the same online location, the forum administrator stated that he wanted to make it easier for readers to find the information they needed. He also hoped that such curatorial work would help the person who had initiated the "misplaced" thread to receive the advice needed, as he thought that placing the thread under an ongoing discussion would heighten its visibility and the chances of it being answered by many.

On the blog, participation was encouraged as many of the posts studied remained in the readers' attention due to the platform owner having opted to mention the posts with the highest number of comments and/or with the most recent comments on the main page. On the forum, online affordances were also put in place to contextualize and indirectly help determine the quality of the shared insights. Thus, next to the username and image used by each online contributor, information was provided about when they had joined the forum and about the number of contributions they had made. Furthermore, online contributors were often reminded by the forum administrator as well as other contributors to provide references in support of their claims, particularly when these were somewhat surprising. The forum administrator also played an active role in enhancing the visibility of certain threads when he considered it necessary, by repositioning them on the first page where the threads overview was provided. For instance, on July 10, 2013, when Ramadan was approaching, he re-positioned a thread initiated on July 29, 2009, as he thought its content may be relevant and helpful to some readers. This thread had been started by *Soleil radieux*, a Moroccan contributor who was interested on how she could combine medical advice regarding Lithium intake with the dietary prohibitions specific to this religious celebration. Thus, thanks to these online affordances and interaction characteristics, it is possible to judge the relevance of a post or thread years later, to identify how the experience of a contributor with a specific medication evolved over time, and to determine how much interactivity a post/thread generated based on the number of comments and the time span in which they were provided.

The analysis of the online data revealed that people diagnosed were aware of current medical knowledge on the treatment of bipolar, as the following three tactics were identified: the mobilization of the notions of uncertainty, complexity, and individualization. Through these tactics, people diagnosed with bipolar disorder reinterpreted the characteristics of the current medical knowledge about the treatment of their condition in view of specific practical goals. Yet, through the accumulation of such exchanges, they went beyond the enactment of lay expertise, and put forward what I call "digitally-informed hypotheses" about the effectiveness of medications. Below I elaborate on how each tactic is developed and for what goals.

3.3.2.1 *Uncertainty*

People diagnosed with bipolar disorder mobilized uncertainty through their ability to locate and manipulate important gaps in relevant medical knowledge, both at the scientific and clinical level, thereby identifying a space which could mainly be furbished through the insights they provided. They thus sought to address medical uncertainty about the effects of certain substances by engaging in experiments. For instance, in a post from November 2011, Tracy argued that N-acetylcysteine (NAC) might be a new cheap and effective supplement in the treatment of bipolar depression. She also mentioned that, while promising, the evidence was limited. In the aftermath, many readers tried NAC and shared their insights. Some of them kept careful track of their self-experiments and shared their experiences at different moments in time, as Table 3.1 indicates.

Table 3.1 Tracking and sharing the results of self-experiments

NAME BLOG CONTRIBUTOR & DATE	COMMENT
Sue, December 2, 2014	I started taking it about 6 months ago after reading your blog about it. I have had no side effects and have had no depressive episodes either. I have had a mixed episode but the depressive symptoms were much less than they would normally be. I'm still cautious about saying it has helped and still monitoring but so far so good. Thank you for mentioning it in the first place. We are all different and some people may have negative effects, that's the same with anything. I would say give it a go.
Sue, December 14, 2015	I've been taking NAC for about 18 months now, I have had no side effects, the depressions have not been as bad and I think possibly the highs are less too. I do get psychosis and I haven't noticed any effect on this. Although my doctor is sceptical I will continue to take it. Hopefully if the trials are successful doctors will be more likely to suggest this treatment. This same doctor recommended glucosamine for my arthritis so it's not that he is against supplements.

These excerpts illustrate how *Sue* enacts lay expertise by closely monitoring her states, by distinguishing between symptoms when assessing NAC's effects, and by evaluating her experiences in light of the amount of time since she started taking the supplement. Something akin to a hierarchy or an attempt at a systematic assessment also becomes apparent, as in both comments *Sue* focuses first on the presence or absence of side-effects, then on NAC's effects on depression, for which it is intended, and only later on its impact on other symptoms. While the first quote reveals the influence online bloggers have upon their readers' treatment, both excerpts indicate the relational way in which people diagnosed make sense of their experiences with medications. In her first contribution, *Sue* solves the dissonance between her findings and those of other people diagnosed by invoking the uniqueness of each person, and echoes Tracy in recommending it to others. In her second comment, experiential knowledge and medical knowledge are described as being at odds with each other, as *Sue*'s tentatively positive findings and intention to continue taking the pills are set against her doctor's doubts. *Sue*'s familiarity with medical knowledge is obvious as she refers to clinical trial results as the type of evidence that can change doctors' prescription practices. Since *Sue* knew that there was a limited amount of clinical evidence available, her sharing activity and encouragement for others to try NAC may be seen as an attempt to help fill these gaps in medical knowledge. Given that *Sue*'s documenting of her states reveals relatively mild improvements, her decision to continue taking NAC also suggests that she may make treatment decisions using lower effectiveness standards than medical professionals. The excerpts thus reveal that medical uncertainty may be a cause for hope in certain instances, and may help to keep people diagnosed motivated and actively engaged with their treatment.

French online contributors re-conceptualized uncertainty to test medical claims about the benefits some of the medications they took for bipolar disorder could have upon other bodily processes. As Table 3.2 indicates, various online contributors shared online insights which they had acquired from their doctors about the neuroprotective effects of Lithium, as well as their own opinions and experiences in this respect.

Table 3.2 Lithium as a neuroprotective agent[11]

CONTRIBUTOR NAME & DATE	FORUM COMMENT
Deepdeep, October 5, 2012	This is what my shrink says: Lithium protects against Alzheimer's. For my mother this seems to be true thus far…. (….) Sometimes I don't know who or what to believe…
nad, October 6, 2012	I've also heard this about Alzheimer's, and also for multiple sclerosis
dallina, October 6, 2012	My psychiatrist at the expert center in Marseille says that lithium reconstitutes the neural connections that explode under the effect of bipolarity. It also protects from Alzheimer's disease. These arguments have tipped the scales even for me, who am a rebel when it comes to taking drugs. I agreed to resume a lithium treatment. I'm starting tonight. He also prescribed Xéroquel.But to that one I say no! I'm still fighting it.
Bipote, Admin_Bipote, October 6, 2012	Apart from that, as Dallina says, the neuroprotective and even trophic effect of lithium is worth mentioning because it opens up new therapeutic perspectives. An increase in the volume of gray matter, especially in the frontal lobe, has been observed in patients undergoing lithologic therapy. A thymic episode is neurotoxic and its repetition can cause neurobiological damage.

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[11] The original quotes in French can be found in Appendix B.

At the time when these online contributors were writing, mechanisms through which Lithium achieved its neuroprotective effects remained unclear (Forlenza et al, 2014). The available evidence about these effects was largely derived from pre-clinical trials and from retrospective registry studies conducted on people diagnosed with bipolar disorder. *Deepdeep* was the first to mention Lithium's neuroprotective effects and she invoked the psychiatrist as well as the experiences of her mother to legitimize these claims, as Table 3.2 indicates. Yet, her concluding remark conveys the uncertainty people diagnosed and carers experienced, the difficulties they had to identify reliable information. These effects acquired more credibility, as more contributors confirmed having heard about them, and having taken the claim seriously enough to base treatment decisions on them (*dallina*). The highest level of credibility ascribed to this view was provided by *Bipote*, who referred to Lithium's neuroprotective properties as a fact, and used medical terminology and the passive voice in order make this claim seem more credible and neutral. The last sentence indicates that he based this perspective on a view of bipolar disorder as a neurological condition, as something that leaves its mark on the brain. This shows the degree to which this person diagnosed had internalized medical knowledge, since many clinical studies which had confirmed this hypothesis were based on neuroimaging techniques (Machado-Vieira & al, 2009; Bearden et al, 2007).

Comparing how contributors on these French and American online platforms re-appropriated uncertainty also revealed important differences in the ways that medical professionals handled the gaps in knowledge and unclarity about the effects of medications. Thus, American online contributors reported taking new medications while at home. Whereas some of them had received phone numbers where they could reach medical professionals if they had significant adverse reactions, others had to rely upon family members and friends to guide them and look after them while they waited to see whether certain initial side-effects would dissipate, while yet others described having to visit the emergency services of various medical institutions. In contrast, many online French contributors reported that significant changes to their medications were conducted while they were hospitalized, which allowed medical professionals to modify dosages, add or remove certain medicines depending on the symptoms they exhibited and on their overall state in a safe environment.

The excerpts above show that reframing uncertainty in terms of tactics is helpful to understand how people diagnosed with bipolar disorder negotiate medical knowledge to turn their personal experiences into valuable contributions. Other complex factors that can influence treatment effectiveness are discussed below.

3.3.2.2. *Complexity*

People diagnosed with bipolar disorder mobilized the notion of complexity as they sought confirmation or additional information from others regarding particular effects they experienced, so that they could use such insights as resources to better negotiate with medical professionals in favor or against the prescription of specific medications. Generics were often mentioned in such contexts by American online contributors. For instance, they invoked the complexity of interactions between the various substances contained in this type of medicines and the role variation in their different dosages may have to put forward the hypothesis that their effectiveness varied:

Table 3.3 The (in)effectiveness of generics

NAME & DATE	BLOG COMMENT
April May, November 5, 2014	Generics…Ugh! This weekend I picked up a refill on my Ativan, which is crucial to maintaining my high level of anxiety not only due to bipolar swings, but also OCD and PTSD. I took the bottle home and the pills looked different. I took them anyway with NO relief whatsoever. I took the bottle down to the pharmacy and insisted they were not what I had been receiving only to be told they WERE. I know what I take and what my pills look like after all this time. A second visit with another pharmacist at the same pharm told me that indeed they had switched generics on me. Did you know that the FDA allows a 20-30% variable amount of the active ingredient in generics. I did not until LOTS of research. You have to be your own doctor AND pharmacist, apparently
Michael, November 5, 2014	My doc told me it's a 40 percent swing.. Issue is the filler.. Different manufacturers use different fillers which can effect how the med is used by your system. Some can come on strong while others are weak.. Many braded pills have 10 manufacturers or more and they are mostly overseas. The FDA could give a hoot. I find that most pharmacists know very little also.. Probably because they have so many different meds to deal with… And, if you notice many generics have gone up in price tremendously since the branded aren't available…Money. Money, Money.

April May's comment is important because it illustrates the various stages and events she underwent until the idea that the generics were not as effective as the brand medicines she had been taking started to take shape. Thus, initially she positions herself as an unsuspecting patient, going for a refill of the prescription. While the different appearance of the pills constitutes a first clue, it is only the lack of effect *April May* experiences after taking them that prompts her to return to the pharmacy several times to make inquiries. It is noteworthy that it is only after her personal experiences about the medication are confirmed by a "traditional" expert, that this contributor takes it upon herself to find more information about generics, their compositions, and pharmaceutical regulation. From a certain point of view, this sequence of events could be seen as tracing her development from the classical "good patient" described by Freidson (1970), who took the pills even though they looked different, and was thus willing to obey and comply with medical advice, to more recent understandings thereof, which conceive of people diagnosed as interested in educating themselves about their condition and assuming an active role in its management. The unfolding of the events also serves to reinforce the unbiased character of *April May*'s claims, as she only becomes distrustful after being confronted with their lack of effectiveness. This exchange is important also because it highlights the reliability of personal experiences about medication and shows that people diagnosed with bipolar disorder take up the role of investigators in order to make sense of them.

This interaction further shows that the blog serves as a space for social learning and consultation, as *April May* felt the need to share the result of her investigation with other people diagnosed, who used the different types of knowledge they were endowed with to confirm the information she put forward. Thus, *April May*'s initial experiential insights acquire more credibility, as they are enriched by the other types of information she gathered as well as by the similar experiences of others and the perspectives they had acquired from medical professionals. The exchange also shows that people diagnosed try to make sense of the varying effectiveness of generics not only by considering the different action of the chemical compounds used, but also by relating it to their manufacturers and to the more or less strict legislation existing in the countries where they are based. Furthermore, these comments indicate that online contributors ascribe the limited or incorrect information they receive from different sources to different causes. Thus, whereas *Michael* believes pharmacists lack appropriate knowledge because they have a hard time keeping up with all the new types of medication that become available, official bodies such as the U.S. Food and Drug Administration (FDA) are thought to intentionally neglect to mention specific aspects or to verify more carefully how certain medications are produced because of their support for the pharmaceutical industry. Since the latter are depicted as mainly motivated by commercial interests, the hypotheses people diagnosed develop based on their personal experiences about treatment acquire more credibility among online contributors. *Michael's* comment thus suggests that the failure of certain governmental agencies to involve and inform the public in more effective ways about its regulatory procedures may have a negative impact on their public image and contribute to shifts in the tasks and cognitive authority of different stakeholders. People diagnosed with bipolar disorder may become more influential and succeed in re-positioning themselves in relation to medical professionals and even researchers through their more active engagement in the production of new knowledge and through the existence of an audience willing to take their insights into account.

People diagnosed with bipolar disorder also re-appropriate the notion of complexity by evaluating multiple factors that may play a role in the development of this condition, and by considering the impact thereof in their responses to treatment. For instance, online contributors often consider treatment response as potentially shaped by time. This may be in line with efforts made by medical researchers to determine the effectiveness of particular substances and "the right time" for their intake. However, while for medical professionals, time is conceived in relation to the developmental stage of a given condition, for online contributors it acquires a more practical meaning. Thus, they relate the effectiveness of particular medications with the time of day when they are taken and with one's bodily state at that particular moment. This was, for instance, the case of Geodon, an atypical antipsychotic which is recommended to be taken with a meal. Whereas in her blog post Tracy described recent study results which specified the number of calories required per meal for this medicine to be effective, online contributors refined these insights by arguing that not only the number of calories influenced treatment effectiveness, but also the specific types of proteins consumed. The following quote is illustrative in this sense:

> I have been taking Geodon (Ziprastadone, I don't know the correct spelling) since around maybe 2001 or 2002. I have this med down to a science. I eat a homemade cheeseburger and a FULL glass of skim milk with my Geodon at 12:30 p.m. and then I drink a small chug of milk at 1:15 p.m. and then finally another cheeseburger and glass of skim milk at 1:45 p.m. If you eat the second cheeseburger and glass of milk any earlier than 1:45 p.m. it will not work and you will be sick for the next 12 hours. Then you must repeat the process at 12:30 a.m. You also cannot drink any water after taking geodon until you wake up. You can take one swig of water here or there but I try not to. One thing that has worked for me is not eating or drinking anything from 9:30 until 12:30. Geodon is a trial and error drug and I have schooled my doctor on what works. (*Kevin*, April 8, 2015)

What is striking in this comment is the level of detail and precision provided by *Kevin*, who states to have expertise about this medication due to the many years he has been taking it. His substantial knowledge is due to the numerous and varied tinkering practices through which he managed to fine-tune what he considers to be the most effective approach to the intake of Geodon. This quote is also interesting because *Kevin*'s recommendation is bracketed at the beginning and at the end of the paragraph by his claim to scientific authority. Thus, even though *Kevin* spells the name of this medicine wrongly[12] and admits to doing so, he claims to be highly knowledgeable about

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[12] The correct name of this medication is Ziprasidone.

it, to the point that he describes a reversal of his position in relation to his doctor. Such statements serve to increase the legitimacy of the insights *Kevin* provides, which is further underlined by the authoritative manner in which he issues his advice. The dissonance between *Kevin*'s incorrect spelling and his authoritative statement suggests that he may consider practical knowledge, with which he believes to be endowed, more important than abstract, theoretical insights.

Other contributors consider the complexity of symptoms of bipolar disorder and the medical, personal, and professional difficulties people diagnosed experience in order to advocate for equally complex therapeutic interventions. These often consist of various combinations of medical treatments, leisure activities, the use of particular objects and specific home decorations as effective therapeutic procedures:

> Have you done EMDR [Eye Movement Desensitization and Reprocessing]? What about a Sun Lamp? There is 1 on Amazon by Sphere Technologies that is $69. It has the highest reviews on Amazon. My friend lent me one and I have been using it for a 8 days. You want to get one that is 10,000 lux and I have seen them as low as $49. (…) I think the sun lamp is worth a shot. It's primarily made for people with SAD [seasonal affective disorder]. I am also going to start volunteering at the animal shelter as a "Cat Socializer". You just go and play with the cats and it makes you feel better, and of course the cats too, and makes them more adoptable. (*Jules*, 2015)

The quote shows that for this particular contributor personal experiences as well as the evaluations provided by others on online platforms such as Amazon represent reliable evidence in favor of taking up particular potentially therapeutic procedures. At the same time, *Jules* is dedicated to providing people with as accurate insights as possible, as he carefully situates his claims by mentioning for how long he had been using the sun lamp and by indicating that it was primarily developed for another condition. This excerpt further illustrates the important financial considerations that people diagnosed with bipolar disorder who live in the U.S. need to take into account when evaluating their treatment options.

Reframing complexity in terms of tactics highlights how people diagnosed with bipolar disorder render the space of medical knowledge more "habitable" by expanding it and adapting it to their own experiences and views on treatment. The comparison between the French forum and the American blog revealed that such experiences were also importantly shaped by social and cultural factors. While the effectiveness of generics was an important topic among online contributors in the U.S., they were not mentioned by French contributors, whose insurance coverage spared them such worries. Financial considerations were among the complex factors online contributors took into account as they evaluated the effects and side-effects of medications. The blog studied here was at times an important venue through which American contributors, who were no longer insured, could benefit from up-to-date insights on available treatments. For instance, they gained access to medical information Tracy or the other online contributors had received and were willing to share with them.

Online exchanges also replaced to a certain extent medical encounters, as some uninsured online contributors, who had to pay out of pocket for medication, used the treatment experiences and information shared by others to determine what medication would be most effective for them. American and French contributors who were insured exchanged information about various factors that might affect the effectiveness of medications in order to share the insights they acquired with their doctors, to determine whether or not to contact other medical professionals when their own doctors were away or, in some cases, to figure out whether their experiences were serious enough to warrant disturbing their doctor while on holiday. At the same time, online contributors from both countries complained about the brevity of medical appointments and the little time they had to actually engage in a conversation with their doctors. From this point of view, online interactions on the blog and forum constituted for them new spaces where the effectiveness of various medications could be talked about in detail, where "digitally-informed hypotheses" could be put forward, nurtured or rejected, depending on the reactions received from others with relevant experiences and knowledge.

The comparison of the ways in which American and French online contributors re-appropriate complexity further reveals that such tactics are influenced by national institutional perspectives on mental health. While American contributors take into account the climate where one lives as an important factor shaping people's reaction to medications, French contributors evaluate their location based on the type of medical services and therapeutic approaches available to them. From this point of view, online contributors on the French forum continue to be supporters of the biopsychosocial model of disease, which, as I mentioned in the previous chapter, was the dominant approach to mental healthcare in France up until the early 2000s. Unlike the U.S., where the biological model had been widely spread since the 1950s, and where people are more used to considering medicines as the appropriate type of treatment, many French online contributors emphasize that they believe treatment effectiveness to be not solely the result of the actions of the various chemical substances they take, but also of various types of therapies and social support. While American contributors also mention different sorts of therapies and provide details about their personal and social circumstances, they are less adamant than their French counterparts about the necessity to tackle bipolar disorder by addressing it simultaneously as a biological, psychological, and social condition. This is a tendency some people diagnosed with bipolar disorder are aware of, as they also criticize what they perceive to be an overreliance on medications among their co-nationals: "You miss 1 day of your Seroquel, or your Cymbalta, or your Depakote… seriously, it will be okay… if not, use your psychotherapy techniques. Oh, that's right… not too many actually do psychotherapy… it's all the meds baby." (*Tabby*, June 11, 2011)

Such distinctions among French and American online contributors also lead to differences in the types of additional therapies they suggest. For instance, French online contributors re-appropriate complexity to combine medicines with therapies that have a more dialogical or interactional character, such as psychoanalytic approaches and eye movement desensitization and reprocessing therapy. While "talk" therapy or Alcoholics Anonymous (AA) meetings are often mentioned by American contributors, approaches focusing on dietary changes and on technological interventions, such as vagus nerve stimulation (VNS), are becoming increasingly popular. Since Tracy has had relatively positive results using electroconvulsive therapy (ECT), she has dedicated numerous blog posts to this therapeutic approach, seeking to dispel some of the negative associations closely linked to it. Overall both American and French online contributors on the platforms studied argued in favor of acknowledging a more diverse array of chemical interactions and practices as influencing treatment effectiveness. Personal preferences also informed the choice of therapeutic intervention, and they are discussed below.

3.3.2.3. *Individualization*

People diagnosed with bipolar disorder creatively engage with medical insights about individualization in treatment response to argue for the recognition of diverse personal preferences and circumstances as important influences on treatment effectiveness. For researchers, such variations refer to the identification of specific, small(er) groups sharing common molecular, environmental, and personal attributes. In contrast, some online contributors interpret individualization so that each person's health and illness trajectory become unique. For instance, people diagnosed with bipolar disorder argue against evidence derived from RCTs in light of the uniqueness of the person diagnosed: "Try not to rely so much on numerical statistics. You see……. you're an individual. Your issues are yours…..only yours….not alike by anyone else…. that makes you very special…..maybe a sad special…..but special just the same." (*Bill*, 2014). Other contributors develop close emotional ties to some of the medicines they use, which is denoted by the frequent use of affective markers when explaining their impact on the contributors' lives. Thus, certain medications are described as "life saviors", "miracle drugs", and they are passionately loved or resented judging by the use of capitals when conveying such feelings. That sometimes online contributors are downright effusive about certain medications is indicated by the quote below:

> Je bénis tous les jours l'équipe médicale qui a découvert les effets du lithium , même si je souffre aujourd'hui de sa toxicité pour mes reins, et je ne regrette pas d'avoir pris ce traitement sur du très long terme.J e lui dois mes plus belles années de vie, plus calmes et sereines que je n'aurais pu l'imaginer.
>
> Le lithium ne coûte, je crois, pas grand chose, il est abondant à l'état naturel.
>
> Comme quoi, on peut avoir la même expérience de bipolaires, et ne pas la vivre pareil...
>
> [I bless every day the medical team who discovered the effects of lithium, even though I'm suffering from its toxicity to the kidneys today, and I don't regret having taken this treatment over a long period of time. I owe it the best years of life, calmer and more serene than I could have imagined.
>
> Lithium does not cost much, I believe, it is abundant in its natural state.
>
> Like that, we can have the same experience as other bipolar people and yet not live it the same way...] (*scabieuse*, October 18, 2012)

This excerpt is important because it reveals that such enthusiasm is not reserved for medications with minimal side-effects or where the side-effects have not yet become apparent. Rather it is the result of a retrospective analysis, in which *scabieuse* assesses both the advantages and disadvantages Lithium brought to her life. This prompts her to become almost lyrical about its positive impact, as the accumulation of superlatives attached to the positively qualifying adjectives in the second sentence suggests. This contribution is also remarkable because it was made as a reaction on a thread where the value of psychotropic drugs was challenged and medical professionals were criticized for their financial interests and close ties with pharmaceutical companies. This explains why *scabieuse* invoked the low costs of Lithium, whereas its being a natural salt was meant to heighten its appeal, to distinguish it from lab-processed molecules, which may have been tinkered with in more complex ways for different purposes. The last sentence serves to nuance this contributor's assessment of the effectiveness of Lithium, as she invokes individualization to account for the different ways in which one could relate to the same bipolar experiences.

Affective markers are important indicators of the confidence online contributors have in the effectiveness of the medications they refer to. For instance, *scabieuse* engaged in various conversations with other people diagnosed with bipolar disorder who were in search for an effective treatment, and every time Lithium was not mentioned on the list of medicines they had taken or were taking at the time, she would warmly encourage them to do so. Such affective and emotional approaches highlighted the effectiveness of specific medications due to their judicious use. Thus, they were reserved only for a limited number of drugs, a fact that the other online contributors seemed to be aware of, judging by their reactions. Thus, whereas scientific approaches to treatment assessment steer away from sentimentality and subjectivity, people diagnosed with bipolar disorder invoke them in their online accounts of their experiences with specific medications as important elements which convey authenticity and lend additional persuasive strength to their accounts. As individual perceptions are accepted as reliable and authoritative by the other contributors, this re-framing of individualization might serve to heighten the epistemic relevance of emotional and affective personal markers in a field where authoritative knowledge has traditionally been acquired based on groups and the calculation of averages.

Online contributors further reinterpret individualization to focus on lifestyle. They provide extensive details about their daily routines, hobbies, professional and familial obligations, alongside information about their reactions to medicines. The quote below is illustrative in this sense, as it shows how an online contributor re-appropriated individualization to expand the meaning of treatment to an activity which falls outside of the medical domain, but which enhanced his wellbeing:

> Dernièrement (histoire toute bete mais moins pour mon cerveau), sortant d'une grosse depression, je suis allé faire de l'equitation, une grande passion... et bien cette seance a été l'equivalent d'un anti depresseur et d'un anxyolitique, j'etais au septieme ciel... zen, bien... et ce mot «bien», on le cherche souvent dans notre maladie. L'effet thérapeutique: ça stimule, ça «zénifie», effet anti depresseur sans virage de l'humeur!
>
> Toi et d'autres bipote m'ont secoué, ma psy... mais très franchement j'en avait pas envie... Il fallait trouver «l'elan», et la machine repartait. Pour le moment je l'ai repris... et je vais nettement mieux.
>
> [Recently (I did something very random though less so for my brain), as I was coming out of a big depression, I went horse-riding, a great passion ... well this session was the equivalent of an antidepressant and an anxiolytic, I was in the seventh heaven ... Zen, feeling well ... and this word 'well', we often look for it in our illness. The therapeutic effect: it stimulates, it "zenifies", it has an anti-depressant effect without a change of mood!
>
> You and other bipolars shook me up, my shrink as well ... but very frankly I didn't want to listen... I had to find the "drive", to set the machine in motion

> again… For the moment I have found it again... and I am much better.] (*cyclone*, Xeroquel, September 6, 2011)

Thus, not only does *cyclone* consider the overall positive effects of horse-riding, but he also compares them to the specific actions of certain types of medications, using terms and approaches from medical practice to explain his state. Since the anti-depressive effect of horse-riding is not accompanied by the risk of mania or hypomania, this contributor seems to suggest it might be better than the categories of medications he invoked. At the same time, the reference to the Buddhist notion of Zen reveals the popularity of meditation and mindfulness as additional approaches used by many to manage bipolar disorder. It further shows that this contributor integrated horse-riding into a broader register of therapeutic practices at his disposal. The effectiveness of engaging in an activity one is passionate about was further highlighted by invoking the difficulties people diagnosed experience when trying to achieve a sense of wellbeing. The second part of the quote shows that engaging in this practice had lasting effects for *cyclone*, as he regained the drive and desire to get well and continued to feel better beyond the specific moment of the riding session. Other people diagnosed with bipolar disorder ascribed such therapeutic effects to the very practice of reading and contributing on online platforms. While the results of studies (Naslund et al, 2016) conducted thus far on the effects of participation in online support groups are inconclusive, some online contributors confirmed *cyclone*'s hypothesis: "this blog and your collective experiences have been better for me than any medications as they usually have side-effects that are not welcomed." (*Edde*, March 24, 2014) In so doing, they expanded the meaning of treatment to a great variety of practices which had beneficial effects for some individuals.

Online contributors also re-appropriate individual responses to treatment in order to emphasize the relevance of their personal experiences compared to medical perspectives and to do away with contradictory claims about the effectiveness of specific therapies. This is how one online contributor reacted to an entry in which medical treatments were praised, while other types of therapeutic interventions were disparaged:

> I strongly disagree. I have used a micronutrient treatment for my bipolar for the past 12 years. It works better than meds ever did at keeping me stable, and without side effects. I don't see it as a cure. It's a treatment. I still struggle at times, but certainly not to the suicidal lows that I did while medicated. The treatment has helped countless (10's of thousands) people regain a life they are happy living. It has been proven to be as effective, if not more effective than medication for the majority of people who commit to this treatment. Just because you deny it doesn't make it truth. The hard part is coming off meds. But there is help available to make that transition. [moderated] (*Kristy Reesor*, 2013)

The fragment shows that *Kristy Reesor* transforms medical insights regarding individual variability in treatment response to strengthen her position and to advocate for a micronutrient treatment. By invoking the difference between “cure” and “treatment”, she draws attention to the limited scientific knowledge currently available in the treatment of bipolar disorder, and depicts this condition as an incurable one. It is also important to consider here how *Kristy Reesor* frames certain statements as stemming from personal experiences while she tries to distance herself from others in order to render them more objective. Revealing in this sense is the switch from the I-statements at the beginning to the “it-sentences” in the middle, where she seeks to show that the relevance of the micronutrient treatment goes beyond her case. The quantitative details she provides serve to rhetorically heighten the credibility of her hypothesis about the effectiveness of this alternative therapeutic approach. The way in which she negotiates its evidentiary status is noteworthy. To protect micronutrient treatment from potential challenges coming from people who may have tried it and had less successful experiences, she introduces the notion of personal commitment as a determining factor, but only in relation to this particular therapeutic intervention. By arguing that the personal accounts of people diagnosed represent valuable evidence, *Kristy Reesor* also brings about a reversal to the ways in which individual experiences are assessed in the hierarchy of evidence which is currently dominant in medicine. Her comment further shows that on blogs people diagnosed with bipolar disorder seek to use their personal experiences to put forward hypotheses about alternative forms of effective treatment in a context marked by important power differences, where the content they share can be censored by blog owners or administrators.

Kristy Reesor’s views on the importance of personal commitment is echoed by other online contributors who interpret individualization in treatment response so as to entail specific personality traits and personal needs. Thus, some comments highlight that characteristics such as risk aversion or tolerance, patience and curiosity play an important role in the treatment approaches people diagnosed try. The quote below reveals how a certain personal character trait or disposition could influence one’s attitude towards a medication and the ways in which its effectiveness is assessed:

> Je crois que la première fois je n’ai pas été assez patiente. J’attendais trop, trop vite. Etre équilibrée, je ne sais pas trop ce que c’est, et j’attendais un afflux d’émotions positives. J’avais vu jusqu’alors la vie en noir, en gris... alors je voulais maintenant la voir en rose, au moins de temps en temps. Alors que la vie normale, c’est pas cela ! Et c’est vrai que j’ai l’habitude de ce trop plein d’émotions. Je suis shootée à l’adrénaline. Je crois que je n’ai jamais connu autre chose, parce que la maladie est apparue très tôt. Je ne sais même pas ce que c’est que vivre normalement...

> de vivre sans lutte, sans excès. C'est bien pour cela que je ne me trouvais pas si malade que cela !!! L'habitude !
>
> [I think the first time I wasn't patient enough. I was expecting too much, too quickly. I don't really know what it means to be balanced and I was expecting an influx of positive emotions. Until then I had only seen life in black, in gray ... so I wanted to see it in pink, at least from time to time. Whereas normal life is not like that at all! And it's true that I'm used to being constantly overwhelmed by emotions. I thrive on adrenaline. I think I have never known anything else, because the disease appeared too early. I don't even know what it's like to live normally ... to live without having to struggle, without making any excesses. That's why I didn't think that I was that sick! By force of habit!] (*dallina*, Lithium, October 7, 2012)

dallina's account suggests that individuals need to be ready for certain medications, that they need to develop appropriate expectations about their effects in order to be able to appreciate them. This is important because it suggests that the performative effect of expectations (Van Lente, 2012) is also applicable when it comes to embodied experiences. At the same time, this excerpt draws attention to the important role of the age at which one is diagnosed, as people who are diagnosed in their youth may not have had sufficient time to acquire deep knowledge of themselves. Furthermore, they may not have accumulated sufficient insights into bipolar disorder and its impact on their lives, to understand that certain manifestations indicate that the medication has been effective. The quote also points to an important element which determines treatment non-adherence among people diagnosed with bipolar disorder, as some of them enjoy their (hypo)manic states and have a hard time appreciating (clinical) stability, which they experience as a flattening of affect.

People diagnosed with bipolar disorder also re-interpret individualization in treatment response online by using different standards to assess treatment effectiveness, as they focus on whether their health allows them to perform various social roles and professional duties or to engage in activities they enjoy. In such instances, they go beyond considerations as to whether or not a certain medication stabilizes their mood, and focus, instead, on the extent to which it allows them to experience the joy of interacting with their children, to fulfill their athletic aspirations or to have a body image that is more aligned to their personal aesthetic ideals. Such accounts are important because they succeed in rendering the effects of specific treatments "thick", meaningful, understandable to people diagnosed as well as undiagnosed. At the same time, they help others decide on the degree to which a certain medicine or therapeutic approach might be worth a try, based on similarities in life circumstances, hobbies, personal values and preferences. These new individualized standards for evaluating a medicine's effectiveness also seem to be importantly shaped by cultural elements. For instance, while many American contributors highlight weight gain as one of the most important drawbacks of using Abilify, an atypical antipsychotic, this side-effect is hardly mentioned by their French counterparts. While it may be the case that French people diagnosed with bipolar disorder are more effective at controlling their weight gain, another possibility is that they prefer to take advantage of the fact that online interactions do not automatically involve seeing each other, to shift the focus away from their appearance in the accounts they provide. This is important because it highlights another way in which the affordances of online platforms may influence the type of insights people diagnosed with bipolar disorder share and the hypotheses they collectively develop online.

Overall, online contributors mobilize individualization to provide insights meant to enable other people diagnosed with bipolar disorder to decide upon treatment depending on their lifestyle preferences, on what they appreciate most about their existence and would like to have restored or improved. Reframing individualization in terms of tactics highlights how people diagnosed with bipolar disorder render the space of medical knowledge about treatment meaningful to them by inscribing in it elements of leisure and experience they found fulfilling. The implications of these findings are discussed below.

3.4 Discussion

This chapter has shown that by re-appropriating medical perspectives and combining them with personal insights, online contributors diagnosed with bipolar disorder go beyond the enactment of lay expertise and develop hypotheses about the effects and side-effects of medications. Blogs and fora enable them to generate knowledge to achieve individual goals, such as finding medicines to better manage their condition while also engaging in activities they value, or becoming sufficiently educated so as to acquire more agency in regard to their choice of treatment in their interactions with medical professionals. As individual requests for advice and information are often followed by reactions which contain detailed descriptions of the effects of various substances, and suggestions as to why they occur, such contributions collectively develop into what I call "digitally-informed hypotheses" about treatment effectiveness. Previous studies have acknowledged the value of blogs in providing people diagnosed with more tailored resources to navigate daily life (Adams, 2010) and have shown that the internet can facilitate collective learning and the development of epistemic communities (Akrich, 2010). Building upon them, this chapter has shown that people diagnosed can engage in the production of knowledge by collectively developing hypotheses through dynamic and even fleeting online exchanges among different contributors.

This development is facilitated by contemporary neoliberal tendencies which encourage individuals to actively engage in their health (Felt, 2015), some of which have already been highlighted in the previous chapters of this dissertation. The findings presented here have shown that when combined with the awareness of medical uncertainty, the cultivation of such pro-active behavior leads people diagnosed to engage in self-experimentation. This is in line with recent literature, which shows that people may undergo risky medical procedures, with limited supporting clinical evidence, as a means to reclaim agency and retain hope (Petersen et al, 2017). At the same time, online contributors' willingness to share their experiences about treatment seems to confirm the emergence of interactive online platforms as spaces for biosociality (Kingod, 2018), where contributors share their experiences and the creative practices they develop to better manage their conditions (Pols, 2014).

While initially people diagnosed with bipolar disorder may contribute online to assist others to achieve more immediate and practical goals, the design and affordances of blogs and fora help turn personal suggestions into hypotheses about treatment effectiveness through the longitudinal accumulation of numerous experiences in the same spaces. This makes it easier for readers to identify commonalities and recurrent patterns and to react to them, even in situations when such observations are not in line with the content of the blog post/thread. Such processes may be facilitated and more readily accepted in the current context in which new approaches to the production of medical knowledge and to the provision of healthcare are tried out. Thus, the growing number of wearable technologies people use and the digital traces they leave behind has made available tremendous amounts of information. This has contributed to an expansion of the conceptualization of what may constitute health-relevant data, as a broad variety of elements, ranging from one's fitness routine to the frequency with which one orders take-away and the type of purchases one makes are increasingly taken into account (Prainsack, 2017; Hogle, 2016). Such an expansion has contributed to and is informed by developments in algorithmic tools and their capacity to collect, aggregate, and discern patterns and correlations in vast, previously unimaginable amounts of data. Apart from large-scale initiatives (Levine, 2018), these developments have also led to various bottom-up projects in the production of new medications, such as local hospital experimentation with the bedside production of medications, where drugs are personalized for individual patients (Moors et al, 2018). Given the increasing popularity of data-intensive resourcing in healthcare and the growing openness towards distributed forms of treatment innovation, the digitally-informed hypotheses developed by people diagnosed with bipolar disorder described in this chapter may be taken up by researchers and, thus, lead to new clinical evidence.

At the same time, the accounts discussed here reveal that the very sharing of personal experiences has an impact upon how evidence is conceptualized and evaluated by people diagnosed. While the recommendations of medical professionals are based on evidence obtained in conditions where high levels of validity and reliability can be guaranteed, the online interactions between people diagnosed with bipolar disorder indicate that they often value insights acquired through the accumulation of personal accounts, whose reliability is indicated through detailed descriptions and the presence of affective and emotional markers next to medical information. This is in line with findings by Bellander and Landqvist (2018), who noted that medical professionals and people diagnosed and/or their carers have contrasting views on knowledge and validity.

Through their comments, contributors show that the effects of medications do not manifest themselves in pristine, laboratory conditions but occur against the messy context of daily life of people with the same diagnosis, but perhaps with different symptoms, bodily reactions, needs and preferences. They suggest that the effects and side-effects of medications depend on the specific circumstances of the lives they act upon, and such knowledge is still insufficient at the medical level. The tendency of online contributors to evaluate treatment effectiveness based on personal needs may be understood as an indication that they require a new type of evidence, better fitted to help them navigate daily circumstances, marked by ambiguity and uncertainty. Such perspectives are in line with the findings of Mazanderani and colleagues (2013:420), who argued that "social media technologies provide patients with novel opportunities for advocating for particular treatments; generating alternative forms of "evidence" built on a hybrid of personal experience and medical knowledge". At the same time, the varying approaches that people diagnosed with bipolar disorder used for their assessment of treatment effectiveness depending on their professional duties and on their personal preferences draws attention to the multiple social identities they draw upon when they seek to make sense of their condition, to acquire substantial knowledge and share their insights. Nevertheless, their diverse and mobile positioning does not mean that they can acquire and make their expertise manifest solely based on individual preferences, insights and experiences. The findings presented in this chapter have shown not only that people diagnosed with bipolar disorder take up and transform current medical insights on this condition, but also that in so doing they reflect cultural perspectives and some of the characteristics of the healthcare system in which they are inscribed. These realizations have informed my view that a new approach to expertise, understood as a practical achievement realized across a complex ecosystem, is more appropriate, since the negotiations and practices through which expertise develops are not only shaped by the skills and position the stakeholders involved occupy, but are also influenced by the legal, economic, and political context in which such activities are undertaken.

The findings presented in this chapter further show that the hypotheses people diagnosed with bipolar disorder develop online are importantly shaped by the lack of sufficient information regarding the processes through which new medicines are developed and brought to the market, and about the ways in which decisions about their use for specific conditions are arrived at. These insights may therefore also contribute to existing literature on pharmaceutic regulation (Moors et al, 2014). For instance, Meijer et al (2013) put forward and tested two types of pharmaceutic regulatory processes: a technocratic model, where only expert opinions were taken into account and a democratic model, where views were developed through a dynamic dialogue between experts and "lay stakeholders". Their findings showed that there were no marked differences between these models in terms of the quality of the process and its outcome, but that stakeholders were more satisfied when using the democratic approach. While Meijer et al (2013) tested their models on pandemic influenza and HIV, the insights I provide in this chapter highlight that a preference for democratic regulatory processes also exists among people diagnosed with bipolar disorder. Since some expectations about and experiences with medications can only be known through dynamic, de-centralized consultations with people diagnosed, the more frequent and consistent use of such democratic approaches to the regulation of psychotropic drugs may lead to greater levels of satisfaction among stakeholders also in the field of mental health and, perhaps, to greater treatment adherence.

The developments described here may also have problematic consequences. For instance, whether or not certain personal insights turn into collectively generated hypotheses is a question of repetition, accumulation, and visibility. As such, they are not only informed by the urgency of certain aspects regarding the effectiveness of specific medications, but they are also shaped by the affordances available on blogs and fora and by people's abilities to use them to their advantage, an aspect that will be explored at length in the next chapter. The fact that information from different years can be located in the same place also has potential drawbacks, as proximity on the blog or forum might obliterate important contextual factors, and unreflectively equate experiences shaped by specific temporal and social coordinates. This may have negative consequences for the reliability of the inferences made based on such insights, as they may lack internal consistency, but also on their validity, since elements that are important to correctly interpret the data used are missing or not taken into consideration. While the de-contextualized use of data is already common in data analytics, many scholars have warned against the consequences such practices may have upon the quality of the scientific claims inferred from them and about the societal transformations they may lead to (Gregory et al, 2019; Prainsack, 2017; Wyatt et al, 2013).

The comparison of the tactics through which American and French online contributors re-appropriate medical uncertainty, complexity, and individualization as treatment response reveals important similarities and differences. Both French and American online contributors engage in online exchanges to achieve specific pragmatic goals, as they try to identify more suitable treatments for themselves depending on their lifestyle and personal preferences, to expand the meaning of treatment to include various practices or to consider its effects in interaction with a more complex array of substances and activities. They also try to acquire more agency in their interactions with medical professionals by having their experiences confirmed by many others. The analysis has also shown that cultural, social, and institutional differences importantly shape online contributions, leading to noteworthy distinctions. Thus, American and French online contributors often focus on different side-effects in relation to the same medication. These differences indicate that more cross-cultural studies on the treatment experiences of people diagnosed with bipolar would be highly valuable, as they may cast light upon important similarities and differences in reactions hitherto considered as mainly biological, and may reveal what factors inform them. The analysis has further indicated that the historical dominance of a biopsychosocial or biological model of disease in a national mental healthcare system leaves durable traces, as it shapes the vision people diagnosed with bipolar disorder have on treatment, the elements they consider to be part of it, and the types of alternative or complementary therapies they are more willing to try. Furthermore, while online contributors from both countries engage in self-monitoring and self-experimentation, French people diagnosed with bipolar disorder test more often new medications in a medical setting and are able to get in touch with their doctor sooner and more often than their American counterparts. Yet, the duration of the medical appointments seems to be equally short.

The findings have also revealed that to a certain extent, the internet allows American and French people diagnosed with bipolar disorder to re-position themselves in relation to medical professionals and scientists, as it enables them to use their experiences to put forward “digitally-informed hypotheses” about the effectiveness of various medications. This medium thus enables them to take a first step toward substantial contributions to the production of clinical knowledge by allowing them to go beyond the enactment of lay expertise about bipolar disorder. While the value of these hypotheses depends on the interest they generate among researchers, the people diagnosed who contribute to their development may thus acquire more confidence in the relevance of their experiences and more determination to shape medical encounters and treatment decisions in ways they find convenient. The internet also makes it possible for people diagnosed with bipolar disorder in the U.S. to regain more agency by redressing, even in a modest way, important inequalities in mental healthcare. Online contributors who were uninsured could acquire indirect access to medical information and advice through the insights shared by those who were insured. They could also learn what medications would be more effective for themselves from the personal experiences of others, thereby reducing personal costs while also circumventing medical institutions and professionals.

To conclude, people diagnosed with mental conditions have been actively engaged in their health for a long time. In a context where medical knowledge has permeated different areas of society, and has, thus, become amenable to multiple usages and interpretations, the internet provides new avenues for them to exchange insights and to contribute to the production of knowledge. Using de Certeau's (1988) theory of creative tactics has allowed me to show that people diagnosed with bipolar disorder develop more nuanced positions than challenging or accepting medical perspectives online, it has enabled me to take their insights and suggestions about treatment effectiveness seriously, and to approach them as productive exchanges which may lead to new knowledge. Thus, by mobilizing the notions of uncertainty, individualization, and complexity, online contributors sought to advocate for specific forms of treatment, to highlight the influence of everyday practices upon treatment effectiveness, and to state the importance of individual experiences as epistemic resources. In so doing, they went beyond the enactment of lay expertise and collectively developed "digitally-informed hypotheses" about treatment effectiveness in an attempt to render the space of their interactions with medical professionals and of daily life with bipolar disorder more comfortable. While people diagnosed contributed collectively to the development of new insights about treatment effectiveness, this chapter also indicated that some individuals had more authority by virtue of their status as blog author or platform administrator. The next chapter will pursue this aspect further and will show that the ideal of active patienthood combined with the skillful use of the internet and an entrepreneurial spirit can render some individuals diagnosed with bipolar disorder highly influential.

Chapter 4

Online expert mediators: expanding interactional expertise

CHAPTER 4

4 ONLINE EXPERT MEDIATORS: EXPANDING INTERACTIONAL EXPERTISE[13]

> Blogs are interesting. They show that humans want to communicate. They show that we want to share our stories. They also became money making opportunities and vanity projects that sometimes make me question my own motives. I am VERY careful about what I share. I am personal without over-sharing. I'm careful of my brand. I protect it every day. I know what I write and I know the effect it has on my audience. (Fast, May 8, 2017, personal communication)

This is how Julie A. Fast, one of the best-known bloggers on bipolar disorder and a person who, based on her own admission, has helped shape this genre, describes this type of interactive online platform and her engagement with it. This quote is impressive in its honesty. It also highlights specific opportunities the internet has contributed to as well as the need for a particular type of expertise in order to be able to take advantage of them. This chapter is dedicated to the study of interactional expertise, focusing on the activities of two highly successful bloggers diagnosed with bipolar disorder.

Relations between important stakeholders in the field of mental health have been significantly transformed by the internet (Barak & Grohol, 2011). This medium has affected the identity and the type of interactions between knowledge producers and users (Wyatt et al, 2013), contributing to the diversification of sources of medical knowledge away from clinical environments (Nettleton, 2004), closer to the everyday settings of people diagnosed (Lucivero & Prainsack, 2015), and leading to the re-appreciation of other types of knowledge (Schaffer et al, 2008). Such changes have taken place in a context where pronounced neoliberal tendencies have introduced a market logic in the provision of healthcare and have encouraged individuals to assume responsibility for their health (Rose, 2007; Novas, 2006). Web 2.0 technologies enable users not only to consume information but also to engage in its production (Lupton, 2014). Whereas the previous chapter has shown how people can enact lay expertise and collectively contribute new insights about bipolar disorder, the focus shifts here to the

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[13] A modified version of this chapter will be published in the special issue "Expertise and Its Tensions" in *Science and Technology Studies*. Whereas the chapter focuses on two bloggers — Natasha Tracy and Julie A. Fast— in the article, the online and offline activities of another blogger –Charlotte Walker— are also discussed.

new entrepreneurial subjectivities (Tutton & Prainsack, 2011) that these technologies have contributed to. I study the online activities of two bloggers diagnosed with bipolar disorder using Collins and Evans' (2002) concept of interactional expertise. I show that through their skillful use of the internet, some individual patients have become highly influential, and argue that this medium has thus helped facilitate the emergence of a new type of stakeholder —the online expert mediator.

First, I consider how the role of patients in mental health has changed over the last decades, focusing on the internet's influence in these transformations. I then flesh out the characteristics of this new stakeholder category by showing that these bloggers become online expert mediators by acquiring or having access to considerable technical knowledge, by enacting interactional expertise about medical knowledge on bipolar disorder, and by expanding their mediation work across various media. Building upon the analysis of their activities, in the last part of the chapter I make a theoretical contribution. I expand the notion of interactional expertise by arguing that it has more of a bi-directional nature than Collins and Evans (2002) and Collins and colleagues (2017) assume, and by showing that it is important to consider the effects of the medium through which it is enacted. As Kivits (2013) argues, the current dominant imperatives to stay or become healthy by seeking and sharing health-related information have contributed to the development of a space where new forms of agency can develop. The findings indicate that through the knowledge they display and the alliances they forge, these bloggers have successfully positioned themselves within this new space, and have expanded their influence beyond that of most authors of illness blogs. In so doing, they have become online expert mediators, a new stakeholder category whose attributes I describe and discuss from a critical perspective.

4.1 Greater mental health patient engagement and the internet

4.1.1 Patient engagement

As many medical sociologists have indicated, since the last decades of the 20th century patient engagement has been promoted in different areas and for different goals (Barello et al, 2014; Turner, 1995), through top-down processes (Hogg, 2009; Godfrey et al, 2003) or as the result of grassroots activities (Rabeharisoa et al, 2013; Landzelius, 2006; Novas, 2006; Kushner, 2004; Taussig et al, 2003; Barbot & Dodier, 2002). The meaning and consequences of patient engagement vary (Rowland et al, 2017; Hickey & Kipping, 1998), yet, as the findings in the previous chapter show, people diagnosed have also come to grasp the conditions of complexity and uncertainty under which medical professionals operate, leading to a growing awareness of the limits of medical expertise. These realizations have had a profound resonance in mental health, where the authority of medical professionals has been challenged since the late 1960s (Pickersgill, 2012), in manners which were discussed in more detail in the introduction to this dissertation. Combined with official restructuring initiatives and considerable openness among people diagnosed towards new approaches and types of knowledge, such challenges have contributed to the proliferation and diversification of mental health professionals (Grob, 2005; Brown, 1988). The relations between existing stakeholders have thus been modified, and the role of patients has changed from passive recipients of care (Barnes & Shardlow, 1997) to consumers who feel entitled to choose the type of care they receive (McLean, 2000). While some patients consider themselves survivors and actively militate against medical conceptualizations and interventions (Whitley, 2012; Speed, 2006; Crossley & Crossley, 2001), many others have engaged in processes of knowledge production (Gillard et al, 2012; Kemp, 2010), evaluation (Director, 2005), and implementation (Davidson, 2005), thereby acquiring a greater role in knowledge production.

4.1.2 The internet in mental health

People diagnosed have used the internet for different types of epistemic engagements. Some patients have used the knowledge thus acquired to question and/or challenge the expertise of medical professionals in several ways (Gowen et al, 2012; Orsini & Smith, 2010; Mulveen & Hepworth, 2006; Fox et al, 2005). Others have engaged in various scientific activities, ranging from monitoring themselves using self-tracking devices and sharing their data with others, to using collaborative platforms, such as PatientsLikeMe, to test medical hypotheses (Kallinikos & Tempini, 2014). Through their use of the internet, such “citizen scientists” or “health hackers” have gone beyond the mere provision and exchange of medically interesting information, connecting with other people with the same diagnosis to “conduct clinical trials on their own diseases” (Bottles, 2013:88), enacting thereby particular values and ideals of patienthood (Sharon, 2017). Such online opportunities have been all the more important in the field of mental health, where study participation has traditionally been difficult, as the symptoms of people diagnosed often rendered their adherence to specific interventions problematic, while the desire to avoid stigmatization made them reluctant to attend face-to-face meetings (Naslund et al, 2015).

Used in mental health since its early days, the internet has importantly shaped the participation of people diagnosed in knowledge production. Already in 1999, Barak (1999:231) noted that “the rapid developments in computers and information technology over the past decade have had an impact on psychology, which has moved (…) from local computer applications to network applications that take advantage of the Internet.” By now, numerous studies have indicated the potential (Smith et al, 2011; Barak et al, 2008; Carlbring & Andersson, 2006; Proudfoot, 2004) and variety of online interventions for mental health (Barak & Grohol, 2011; Kraus et al, 2010; Marks et al, 2007; Ybarra & Eaton, 2005). Bipolar disorder is among the mental health conditions affected by such approaches, as various online therapies and different types of mobile phone applications have been developed (Nicholas et al, 2015).

There are important differences in approach, motivation, and goals among patient organizations focusing on the same condition (Barbot, 2006) and even among members of the same group (Epstein, 1996). The internet has helped render more visible the heterogeneity of bipolar patients, as various online platforms testify to their different needs and preferences. It has also contributed to the emergence of new types of involvement for people diagnosed with bipolar disorder, by diversifying the range of stances at their disposal. By using the internet, they have been able to develop new skills and to acquire various resources. This has not only rendered bipolar patients more salient stakeholders, but it has also contributed to a diversification of the type of stakeholdership they could take up.

4.2 Illness blogs

Since the emergence of surveillance medicine in the twentieth century (Armstrong, 1995), and particularly after the adoption of a consumerist culture in healthcare (Lupton, 1995), individuals have been encouraged to engage in self-surveillance practices and to actively manage their health by staying informed. The development of digital technologies has contributed to the diversification and intensification of these tendencies (Kopelson, 2009), but has also "promoted the individual expression of a personal experience of health" (Kivits, 2013:222), as people have been increasingly exhorted not only to seek information but also to share personal insights. Thus, the internet has enabled not only patient groups, but also individuals to become influential by achieving high levels of visibility and by acquiring numerous readers. While most researchers have studied the changing identity and growing influence of patients as the result of collective actions, several academic works have highlighted the importance of particular individuals in shaping the character of patient organizations and of their interactions with medical professionals (Lerner, 2001; Klawiter, 1999). This chapter contributes to the literature by showing that some individual patients have become highly influential in mental health by taking advantage of some of the opportunities generated by the development of web 2.0 platforms in the context of growing tendencies to responsibilize individuals for their health (Nettleton, 2004).

Among the multiple forms of self-expression the internet has enabled, illness blogs represent a highly popular genre (De Boer & Slatman, 2014). Given their popularity, malleable architecture, and primarily individual character, blogs represent an excellent site to study the activities, knowledge practices, and alliances through which individuals achieve an influential position. Illness blogs are a specific type, as they "are used to express the experience of illness and to connect with readers via the internet" (Heilferty, 2009:1542). They differ based on their design, accessibility, and interactive character, and it is the more or less skillful combination of affordances related to these aspects that largely determines a blog's standing.

4.3 Two bloggers on bipolar disorder

On December 3, 2016, an online search using the keywords "bipolar blog" generated 12,600,000 results in Google, and 6,870,000 on Yahoo. Regardless of search engine used, the blogs of Natasha Tracy, which was discussed from a different perspective in the previous chapter, and of Julie A. Fast came up on the first page of results, either directly or mentioned under rubrics such as "the best bipolar blogs of the year" on several health platforms. They are thus likely to come to the attention of many internet users, especially since both of them can be accessed freely by readers.

Each of these bloggers has been diagnosed with bipolar disorder for about two decades. Tracy is a self-styled "social media strategist" and a writer on topics such as bipolar disorder, depression, pharmacology, and other mental-health related issues. She has authored three blogs: *Breaking Bipolar*, *Bipolar Burble*, and *Bipolar Bites*. Her blogs attract large numbers of visitors, and many of her posts receive hundreds of comments. Fast introduces herself as "a world leading mental health expert on the topics of bipolar disorder, depression, seasonal affective disorder, personality disorders and mood management". She claims that her site and blog together have been visited by one million visitors. Unlike Tracy, her personal blog, *Bipolar Happens!*, only gathers a very modest number of comments (< 10), but there is significantly more interaction on her blog on the bipolar disorder "Hope" magazine website, *Fast Talk*. Fast also works as a "bipolar disorder management specialist" at Share.com, the website created by Oprah and Dr. Oz.

While internet users have been studied as health-related information seekers and/or producers, less attention has been paid to their potential as information mediators. Illness blogs are important mediation sites, as experiential knowledge is combined with medical, pharmaceutic, and socio-economic information. Through their activities, these bloggers function as mediators in the sense Latour (2005) put forward when discussing how a definition of the social is related to audiences. In explaining the main differences between the ways in which sociologists of the social and sociologists of association define the social and the means by which the social is achieved, Latour (2005) distinguished between intermediaries and mediators. While intermediaries transport information without bringing any modification to it, mediators "transform, translate, distort, and modify" (Latour, 2005:39) it. They do so to adapt it to the opportunities and limitations of the medium and to the requirements of different audiences (Wathen et al, 2008). Importantly, the development of this new stakeholder category occurs in a context where patient experiences have come to be valued, elicited in various ways online, and, subsequently, commodified (Lupton, 2014; Adams, 2013; Mazanderani et al, 2012). I argue that through their practices and collaborations with different stakeholders, these two bloggers move beyond the role bipolar patients generally have in the field of mental health, and turn themselves into a new type of stakeholder —the online expert mediator.

4.4 Theoretical framework

Several concepts have been developed by medical sociologists and anthropologists that could be applied to study the knowledge of these bloggers, some of which have already been mentioned in the previous chapters. I shall briefly refer again to them here, focusing this time on the aspects that are particularly relevant for this case study. Borkman (1976) put forward the influential notion of experiential knowledge, denoting individual, concrete and situated insights acquired through one's personal experience with disease. Importantly, experiential knowledge can underpin one's claims to authority, while its cathetic dimension is conducive to trusting exchanges. Through her notion of lay expertise, Arksey showed that people diagnosed can become knowledgeable enough "to reverse the usual doctor-patient relationship and instead stimulate a two-way learning process" (Arksey, 1994:445). Building upon this notion, Epstein (1995) argued that patients can develop sufficient scientific knowledge to shape medical research and to modify study design and methodology. As some scholars argued that specialized knowledge cannot be held by non-specialists (Prior, 2003), and finding experiential knowledge too vague for analytical purposes, Pols (2014) put forward the already familiar concept of patient knowledge. Defined as "practical knowledge that patients use to translate medical and technical knowledge into something useful to their daily life with disease" (Pols, 2014:73), it can be made "useful and transportable to others" (Pols, 2014:78). Patient knowledge focuses thus on the development and transmission of techniques for living with disease in good ways, but not on the patients' substantial engagement in medical research. While important, these notions are insufficient to analyze the diverse resources of these bloggers and the broad activities they engage in.

Their online activities are analyzed instead using the concept of interactional expertise (Collins & Evans, 2002), which bridges the divide between practical, experiential and scientific knowledge. This notion is particularly useful, because it allows me to identify people endowed with substantial knowledge but missing official credentials, and provides an appropriate explanatory framework when studying phenomena "involving different expert communities" (Collins et al, 2017: 782). While contributory expertise denotes one's ability to contribute productively to a field (Collins & Evans, 2007), interactional expertise has been recently refined into "fluency in the spoken language associated with a practice" (Collins et al, 2017:765). Importantly, "what distinguishes interactional expertise is the claim that, under the right social circumstances, fluency in a spoken language and a conceptual understanding of the domain to which it refers, can be acquired without experiencing the practice." (Collins et al, 2017:765) Thus, people may acquire interactional expertise through immersion in a field, while following a different trajectory than contributory experts (Collins et al, 2006). Even though they lack accreditations, interactional experts hold specialist tacit knowledge and can reach such high levels of knowledge that contributory experts welcome conversations with them. Interactional expertise is also highly specific: just like contributory experts in a field can contribute successfully only in some areas, interactional experts can be more competent about particular subdomains of a field. Furthermore, the acquisition of interactional expertise enables people to function as mediators between contributory experts in a field and the group(s) they represent.

Collins and Evans (2015; 2017) have studied interactional expertise using the Imitation Game, which is an adaptation of the test Alan Turing developed to assess the intelligence of computers. The Imitation Game consists of three players: a judge from the domain of interest, who creates questions and sends them to the other two players; a non-pretender selected from the same domain, who is asked to answer the questions naturally; and a pretender, that is, someone from a different group, who is asked to answer the questions as if s/he were part of the target domain. Collins and Evans (2015) hypothesize that the pretender has interactional expertise in the domain of interest, if by comparing the two sets of answers, the judge cannot distinguish between those s/he and the non-pretender provided. By now, the Imitation Game has been used sequentially and non-sequentially, both for qualitative and quantitative research, as research method as well as an intervention meant to contribute to a fruitful dialogue between participants upon the game's completion. In the medical field, the Imitation Game has been used to study the degree to which specific types of medical professionals are able to discursively take up the perspectives of people diagnosed with various conditions (Evans & Crocker, 2013).

For Collins & Evans (2015), the Imitation Game continues to be the preferred method to test interactional expertise, as it allows them to resist calls to expand the initial definition of the concept in ways which they believe would diminish its "real" character. Nevertheless, in this chapter I follow the lead of scholars who have argued for a broadening of the way in which interactional expertise is understood (Goddiksen, 2014). I thus take up Plaisance and Kennedy's (2014) recommendation to study interactional expertise by considering the "fruitful" contributions people endowed with it can bring to a field due to "the various profiles that interactional experts can have as a result of who they are, why they've sought to acquire IE [interactional expertise], and how they make use of it" (Plaisance & Kennedy, 2014:65). In so doing, I extend interactional expertise by considering the effects of taking seriously the medium through which it is displayed and I show that it has more of a bi-directional character than Collins and Evans had envisaged.

Interactional expertise can play an important role in the relations between medical professionals and patients. Considering chronic illnesses, for instance, Collins and colleagues (2017) suggested that it would be worthwhile to study the level of expertise medical professionals have regarding their patients' lived experiences with particular conditions. While this is not the object of this chapter, their suggestion reveals that the experiential knowledge of patients is an area in which medical professionals might be interested to become competent and for which they require the assistance of their patients. This also means that while medical professionals are contributory and interactional experts in regard to (specific areas of) medical knowledge, they generally lack expertise regarding the lived experience of a condition. Unlike them, people diagnosed have contributory and interactional expertise regarding the latter aspect, but developing interactional expertise in the medical field is an accomplishment in which only some of them succeed. Thus, in this chapter I show that people endowed with interactional expertise can successfully influence the audience of bipolar patients and their families to whom they translate medical knowledge, and they can also collaborate with medical professionals. I argue that there are important differences between the activities people can engage in and the approaches that they can choose from to display interactional expertise, depending on the medium they use.

Each medium offers specific opportunities and provides different limitations, which people can react to depending on their skills and other resources. While some of them may be able to understand their interlocutors better and express themselves more eloquently during face-to-face encounters, they may have a more difficult time displaying their interactional expertise convincingly via the telephone, in writing, or online. Furthermore, each medium might bring them in touch with different audiences, with different criteria for assessing credibility, different expectations and informational needs. By studying the activities of Tracy and Fast on different online platforms, I identify various ways in which these bloggers make use of online affordances in order to successfully deploy interactional expertise and thereby establish themselves as authoritative figures in the field.

4.5 Methodology

In analyzing how the bloggers display interactional expertise, I take a mediated perspective, whereby I consider the content they produce not only as the result of their particular skills and intentions, but also as importantly shaped by the technology of blogs, which facilitates particular behaviors and practices, but constrains others (Kivits, 2009). I aimed to mimic the approach of regular users, and selected these bloggers using the Google index as a relevance indicator. Data were collected between July 2014 and September 2018 and initially consisted of: the bloggers' posts about the treatment of bipolar disorder and information provided under the "about" rubric of every blog (see Appendix C for an overview of the blog posts where the quotes used in this chapter come from). The direct mentions and hyperlinks on their blogs allowed me to become aware of the medical professionals and public officials Tracy and Fast knew and of the institutions they had ties with. In order to acquire a better understanding of their standing, information on their other public activities and on the signs of recognition they had received was needed. Additional online queries were therefore subsequently conducted, using the bloggers' names as search terms in the search engine Google. The search "Natasha Tracy" generated 19,600,000 results, while "Julie A. Fast" 349 million. The biographical and social data were collected from the first ten pages of results. I also conducted an email interview with Julie A. Fast and used the data in my analysis (section 7.1).

I performed thematic analysis of all the texts collected, including hyperlinks and images, by identifying important themes through repeated readings (Lupton, 1997). Given the bloggers' online standing, the initial coding process focused on (1) the type of information they made available about bipolar disorder on their blogs, with the themes identified including: treatment, management of the condition, lived experiences of people diagnosed broadly understood, and (2) on their interactions with readers, which were roughly thematized into provision of (emotional) support, provision of additional information, reactions to challenges, and reactions to positive feedback by the bloggers. Based on these preliminary findings and in consultation with the literature, the coding of the data was subsequently refined in line with the notion of interactional expertise. I operationalized interactional expertise based on Collins and colleagues (2006) into three main dimensions: linguistic fluency in the field of medical knowledge about bipolar disorder; ability to evaluate and distinguish between medical professionals; ability to provide practical advice about relevant matters in the field. Given the aim of expanding the notion of interactional expertise by focusing on its bi-directional character and by considering the effects of the medium through which it is articulated, the following aspects were additionally focused upon using also the biographic data collected: how and when the bloggers invoked and displayed medical knowledge; the bloggers' relations with medical professionals; the alliances they forged; elements conveying the bloggers' standing; the bloggers' use of online affordances. In the following sections, I show that these bloggers enact interactional expertise and that they have turned themselves into online expert mediators through a substantial use of its bi-directional character and by expanding their mediation work online and offline.

4.6 Tracing the development of a new stakeholder category

4.6.1 Technical prowess

A first characteristic of online expert mediators is their endowment with or access to substantial technological skills. Fast and Tracy managed to become online expert mediators because they were among the first to realize the internet's potential and to understand how much people diagnosed with bipolar disorder needed their insights. While Tracy used to work for Microsoft, which suggests she is knowledgeable about computers, Fast's long-term partner at the time when she started sharing her perspectives on bipolar disorder online was a gifted programmer. She also mentioned that both of them were technology enthusiasts. In the e-mail interview I conducted with Fast, she stated that her "internet career was a perfect storm of events" (Fast, May 8, 2017, personal communication), as at the time when she had finished her first books, she found out about the existence of download books. The following excerpt reveals the important role various technologies and her and her partner's abilities to make use of them have played in her career:

> In that EXACT moment in the spring of 2002, I had the idea that I could take my first two books and sell them as download books. No one was doing this except a few guys who were selling sales tools and real estate guides. I found NO books on the internet about any psychology topic or even any self help topics. I knew I had a good idea. (…) We spent the next month building a website to sell my two books. I turned my manuscripts into PDF files and because he was a programmer and a computer genius- we were able to build something that hardly existed at the time. An ebook website! The books were Bipolar Happens! and my Health Cards Treatment System for Bipolar Disorder. I wrote a home page- Ivan created links for people to buy the books through something called a SHOPPING CART and the business was born. It wasn't that long ago, but can you believe that the words Ebooks and shopping cart were so new, we were not

> even sure what they meant. My business helped define the process. I was the first person in the world to sell a psychology or self help ebook online. (my emphasis)
>
> I say it was a perfect storm because on the exact month that I started my webpage, Google started something new called ADWORDS. I was one of their first customers. I created an ADWORDS account and started to advertise my treatment plan from the first week it was online. This was perfect timing. Believe me, so much of what happens online is LUCK. Yes, I was prepared and I had a truly great product, but the timing was perfect. Often, you have to be in the right place in order to adapt new technology. (Fast, May 8, 2017, personal communication)

The first paragraph of this excerpt reveals the innovative character of Fast's approach, both regarding the content she developed as well as the technologies used to make it rapidly available to large audiences. It also suggests that the considerable influence she enjoys today is partly due to the fact that she played an active role in the development of the field of self-help e-books from its inception. From one point of view, the online technologies she used had an empowering effect for her and presumably for Tracy as well. Fast stated that "I was sick a lot- so having an internet business was a miracle for me. I could be sick and still sell my books." (Fast, May 8, 2017, personal communication), while she later reiterated that "[a]n internet business is the ONLY business I can do considering my brain limitations" (Fast, May 8, 2017, personal communication). She thus emphasized several times that it was the specific character of online communication, which allowed for advanced planning and for newsletters and subsequently blog posts to be made available online, regardless of her actual state of health, that enabled her to work and achieve professional fulfillment despite the severity of her condition and of other health challenges. Yet, the second paragraph shows how important Fast considers timing and the early development of relevant relationships to have been for her online career. Fast's early start using one particular online technology enabled her to be among the first to embrace many others, which were subsequently developed. From another point of view, these online technologies also contributed to important inequalities, as her status as a successful early adaptor provided her with more authority and influence than people who started using them later, thereby enabling her, for instance, also to shape the genre of illness blogs, according to her own admissions. Fast's substantial online knowledge allowed her to increase her online visibility, as she mentioned that "I also feel… these three sites [her sales website, her PR page, and her blog] have helped with Google rankings" (Fast, May 23, 2017, personal communication)

Fast also highlighted the importance of adaptability and credibility for such online undertakings. Pondering upon the way in which her three websites had merged, and on the fact that an update was overdue, she stated that

> It's important to know that the internet is incredibly ALIVE- we do things that you can't do in a regular business. (…) So many internet business decisions are creative instead of business oriented. Creative people like myself- who don't really like looking at site stats and comparing what site works better than the other, tend to just leave things online and add to them. Eventually, we hire someone and re do it all with better analytics. (Fast, May 23, 2017, personal communication)

This excerpt reveals that many aspects regarding her online platforms and the online affordances available on them are not always the result of strategic thinking and careful consideration, but they often develop as quick reactions to specific challenges or transformations. It also shows that more people contribute to the success of these highly influential individuals, and that the bloggers themselves need to call upon many different types of knowledge. Fast's discussion on the use of social media suggests that specific types of expertise may be required for the successful use of each of them:

> THEN, Facebook happened. I can't tell you enough how this changed everything. MySpace simply couldn't do what Facebook did. Facebook made talking about yourself very easy. I had a love/hate relationship with Facebook for many years. I was bullied a lot and didn't know how to control the flow of information. Webpages and blogs are safe spaces- the author controls who says what. Facebook was a free for all. It was amazing and destructive at the same time. I know know exactly how to use it, but it's an art. I can say the same for Twitter. (Fast, May 8, 2017, personal communication)

This quote reveals the multitude of online skills that these bloggers have had to develop throughout their online trajectory, as Fast's interview answers could also be read as a fascinating personal piece of history on the development of social media and the introduction of various online technologies. This excerpt also testifies to this blogger's awareness that certain online platforms afford greater control and power than others, and that appropriate skills need to be acquired to be able to handle the challenges posed by each type of online platform and use them to one's benefit. Thus, just as the internet is multiple, so need the skills required to use it in one's favor need to be, and developing such insights requires time and numerous other resources that few people may have at their disposal.

4.6.2 Interactional expertise

Next to technical skills, Fast and Tracy also needed to develop and enact interactional expertise about medical knowledge on bipolar disorder to successfully function as online expert mediators. The display of linguistic fluency in a field is the main mark of people endowed with interactional expertise (Collins & Evans, 2002). While Tracy and Fast are not medical professionals, nor did they study medicine, the many years since they have been diagnosed with bipolar disorder, the multitude of treatments they have tried and the great variety of professionals they have consulted have provided them with ample opportunity to observe the practices of the medical community. Furthermore, their own pro-active attitudes have enabled them to deepen their medical knowledge about bipolar disorder. These bloggers display their linguistic prowess throughout their posts and interactions with commentators, as they explain medical phenomena using a more accessible vocabulary and providing examples, they give advice about the most appropriate therapeutic approaches depending on one's symptoms and/or life circumstances, and are aware of the latest developments in the field. The excerpt below is illustrative of such activities:

> Drug tolerance is also known to occur upon drug-discontinuation. In other words, someone who has previously responded well to lithium discontinues the drug, symptoms reemerge, the person goes back on lithium but does not find it effective. Again, we don't know why this occurs but it does appear to in a small percentage of patients. In one study, it occurred in 13.6 percent of people taking lithium.
>
> (...)
>
> Warning, this is a preclinical study and as such the implications from it may not be fully understood. Please make sure to make any medication changes only with doctor oversight. For more information please see the study Tolerance to the Prophylactic Effects of Carbamazepine and Related Mood Stabilizers in the Treatment of Bipolar Disorders [hyperlink provided]. (Tracy, Bipolar Bites, May 30, 2012)

This quote indicates Tracy's position as mediator between medical professionals and bipolar patients, a position which I argue is characteristic for this new type of stakeholder. While it may be that it refers to the level of knowledge available to the whole of humanity, the use of "we" in a context where study results are discussed suggests that Tracy sees herself more as a member of the medical community. At the end of the post, however, she reclaims her subordinate position to medical professionals, while by sharing the source she used, Tracy reveals her awareness of the need to legitimize her claims.

Mediators importantly transform the meaning of the information they transmit and this is obvious in the posts authored by both bloggers. While they convincingly use medical vocabulary, they do so in particular ways. For instance, in a manner which reiterates the tactic of individualization discussed in the previous chapter, Tracy puts forward her own reading of personalized medicine, as on numerous occasions she seems to believe that each person displays an individual mix of symptoms and reacts differently to treatment, as the quote below illustrates:

> And if 99 people say the med is bad, but 1 says it's good, what benefit is that? Should the patient not try it? Should the patient assume the med won't work or will have too many side effects? The 99:1 ratio essentially means nothing because we're all different. (Tracy, Breaking Bipolar, June 30, 2011)

Furthermore, Tracy often uses statistics and results obtained through randomized controlled trials to support her claims. This shows that she makes strategic choices about the ways in which she refers to medical information, an approach previously identified among patient organizations (Treichler, 1999). This rather complicated balancing act is necessary as it allows her not to alienate readers with experiences different from the ones she describes, while maintaining her authority. At the same time, it enables her not to stray too far from the prevailing medical consensus, thereby retaining her ties with the medical community.

The bloggers display their linguistic prowess also by distinguishing between different medical professionals in the field of bipolar disorder and they often criticize the prescription habits of general practitioners, as the quote below illustrates:

> Interestingly, many fewer people being treated by bipolar disorder experts are on antidepressants:
>
> - Treated by community psychiatrists—80 percent of patients are on antidepressants
> - Treated by mood disorder clinics—50 percent of patients are on antidepressants
> - Treated by specialty bipolar clinics—20 percent of patients are on antidepressants
>
> So it would seem that the more specialized the care, the more professionals recognize the concerns over antidepressants. (Tracy, Breaking Bipolar, July 10, 2013)

As such views are expressed in posts where they provide the latest insights into a particular treatment, it would appear that these bloggers position themselves as more up-to-date than some medical professionals. Since Collins and Evans' (2002) conceptualization of expertise is based upon the idea that no contributory expert is equally competent in all areas pertaining to a particular domain, it remains open for debate whether such online contributions are meant to be understood as epistemic gaps which the bloggers seek to fill or whether they represent interventions through which they challenge the authority and standing of medical professionals who are lower positioned than specialists and scientists, for instance. This ambiguity is further exacerbated by the fact that such online comments are balanced by entries where Tracy and Fast warn readers about their lack of medical credentials and take up a complementary function to medical professionals. They try, for instance, to prevent people from quitting their medication when scandals related to pharmaceutical companies emerge. Fast even depicts herself (and people diagnosed) as useful allies, helping doctors identify dishonest claims made by pharmaceutical companies through their experiential knowledge of the effects and side-effects of medications (Fast, Bipolar Happens!, October 16, 2016). Furthermore, multiple entries (Tracy, Breaking Bipolar, July 5, 2012) show that through their immersion in the community of medical professionals, these bloggers have also become familiar with the political economy of the pharmaceutical industry. Another way in which they display their fluency in medical knowledge is by evaluating the merits of various studies and by distinguishing between medical information based on its source. In so doing, they often clarify the status of the knowledge on bipolar disorder currently available and the inferences that can be made on it, as the following excerpt indicates:

> It's time to get clear on what we really know about brain scans and #bipolar. It's so frustrating to read articles and studies about bipolar and brain imaging. At this time, there is NO brain image scan for the diagnosis of bipolar. Please do not pay someone who tells you that they can determine bipolar from an MRI or PET scan. It simply isn't true.
>
> This is nascent science. One study shows some grey matter thinning in 3000 patients, another shows 'abnormal' activity in the amygdala and frontal lobes. There is nothing definitive and even if someone did find a change in the brain, without having a management plan that works, the information is just that.. information. (Fast, Bipolar Happens!, July 18, 2018)

This excerpt is important because it shows that Fast has enough scientific knowledge to distinguish hopes and visions from the current relevance of brain scans in the diagnosis of bipolar disorder. She is also aware that numerous procedures need to be in place in order to turn scientific insights into improvements at the level of clinical practice, so that people diagnosed can benefit from them. Fast enacts interactional expertise by showing her familiarity with medical technology and terminology, as she describes the regions of the brain that may be implicated in the development of this condition using medical terms. This quote also illustrates Fast's concern for the quality of information that people diagnosed may acquire, even from medical sources, and shows that she positions herself as a mediator, by using her own knowledge in order to correct erroneous assumptions and expectations. The bloggers also enact interactional expertise through their careful selection of the sources of information they use in their posts, as the excerpt below shows:

> I'm pretty fussy about which medical and mental health resources I like, and which ones I don't. While there are many bipolar and mental health resources out there, I'm only interested in accurate *verifiable and reliable* sources of information on bipolar disorder and mental illness. (Tracy, Bipolar Burble, *Bipolar and Mental Health Resources*[14], emphasis in the original)

Through their online posts, these bloggers show that they are endowed with sufficient medical knowledge (both substantive and methodological) to be able to distinguish between professionals based on their training and prescription habits, and that they can correctly interpret the results of scientific studies. Furthermore, they provide ample advice about the treatment and management of bipolar disorder. Tracy and Fast thus show that they have become fluent in the language of medical professionals and have therefore successfully developed interactional expertise.

4.6.3 A strong media presence

While important, having (access to) considerable technical skills and developing interactional expertise are not sufficient for these bloggers to become online expert mediators. To function as successful mediators between medical professionals and people diagnosed, Fast and Tracy not only require ample opportunities to enact interactional expertise, but they also need a strong media presence, to increase their public visibility and standing. The two bloggers have achieved this by developing close relations with mass media outlets. Tracy has often been interviewed and has participated in documentaries about bipolar disorder. In 2008, Fast hosted a weekly radio program, *The Julie Fast Show*, on KTRO in Portland, during which she had a number of "special guests", medical professionals or people diagnosed with various mental health conditions, who often wrote about their experiences and participated in advocacy actions. She is regularly interviewed on diverse mental health issues, such as pop artist Britney Spears' nervous breakdown and actress Carrie Fisher's death, and writes on mental health in magazines

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[14] https://natashatracy.com/bipolar-and-mental-health-resources/. Accessed on May 13, 2016.

such as *People* and *US Weekly*. Fast was also the original consultant for the character played by Claire Danes, the main protagonist who suffered from bipolar disorder in the popular drama series *Homeland*. Fast and Tracy have also published books about their experiences with bipolar disorder, thereby further extending their reach. In 2016, Tracy wrote *Lost Marbles: Insights Into My Life with Depression and Bipolar*. Fast is the author of five books, which have sold over 250,000 copies, four of which are "on the Amazon.com mood disorder bestselling book list" (Fast, Bipolar Happens!, 2016). Through such activities, the bloggers also reach broader audiences than bipolar patients and their families, thereby contributing to how bipolar disorder and other related conditions are understood by the general public. As they become more familiar with other media, these bloggers can use their skills for more political purposes, as they may generate public sympathy, emphasize the urgency of particular pieces of legislation or treatment provisions, or put forward more complex images of life with bipolar disorder. In so doing, Tracy and Fast expand their mediation work beyond the more immediately responsive online medium, translating, synthesizing, bringing together, and refining different types of knowledge about bipolar disorder in formats in which interaction is more difficult, takes more time, and occurs more frequently away from the public. Yet, it is precisely through their ability to use different media and to retain a coherent image across them that these bloggers further increase their influence and standing.

That their standing goes beyond that of the average blogger is indicated by the numerous awards Tracy and Fast have received. Tracy received the Beatrice Stern Media Award and the #ErasingtheStigma Leadership Award, and has been listed as the fourth Health Maker in the top ten online influencers in the area of mental health by Sharecare.com. She was also a speaker at the National Council on Mental Health and Addictions Conference and is hailed as one of the "heroic" figures of people diagnosed with bipolar disorder. Another indicator that her reach goes beyond the small circle of family and friends of regular illness bloggers is the fact that she has been a contributor on health platforms and a subject matter expert on bipolar disorder at Answers.com, all of which have millions of visitors. Fast received the Mental Health American Journalism award for the Best Mental Health Column in the U.S. Furthermore, the blogs both Tracy and Fast authored have been voted many times among the best bipolar blogs.

Whereas Fast's and Tracy's activities across multiple media help them acquire greater audiences, the distinctions they received function as references or recommendations. Consequently, they can use their public visibility and standing as important resources to facilitate the development of more varied and substantial collaborations, not only with people diagnosed, but also with medical professionals. While this is an important characteristic of online expert mediators, in the next part of the analysis I use these insights to also make a theoretical contribution, by expanding the notion of interactional expertise. I do so by arguing that interactional expertise has a stronger bi-directional nature than Collins and Evans assume, and that the effects of the medium through which interactional expertise is enacted need to be taken seriously.

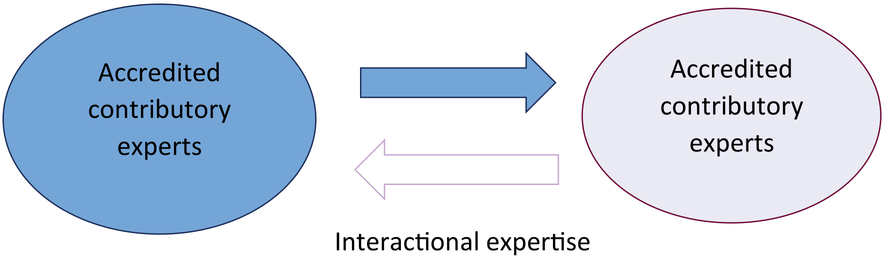
4.7 Online practices and theoretical implications for interactional expertise

4.7.1 Substantial interactions and bi-directionality

Bi-directionality refers to the ability of people endowed with interactional expertise to function as mediators between others with the same kind of contributory expertise as they and with individuals who have contributory expertise in the field where they hold interactional expertise. Whereas bi-directionality is an important aspect of interactional expertise, Collins and Evans do not sufficiently theorize it. For Collins and Evans (2002), interactional experts translate the practices of contributory experts in one field for people with contributory expertise in another field, and shape the knowledge contributory experts produce by questioning some of their practices or by making them aware of other perspectives on an issue of interest. Thus, Collins and Evans see interactional experts as providing contributory experts with sources of inspiration. Whereas they see such exchanges as taking place both in conditions of symmetry and of asymmetry, in the latter case, they only seem to conceive of one direction for the acquisition of interactional expertise, as I explain below.

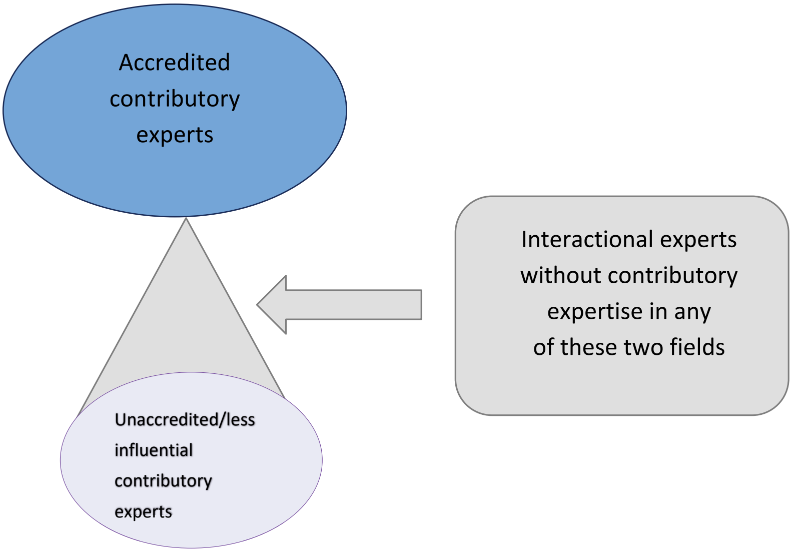
Collins and Evans (2002) do not provide much information about the acquisition of interactional expertise in conditions of symmetry, but they suggest that it occurs between experts who may find themselves equally well positioned in order to productively contribute to the solution of a certain problem. In such conditions, Collins and Evans (2002) state that any of the two groups may absorb the expertise of the other one by developing interactional expertise, as Figure 4.1 indicates. One may imagine such a situation occurring, for instance, as two different types of medical professionals are consulted for the treatment of a difficult case. Which one of the two specialists takes charge and oversees the patient's treatment is "arbitrary" from Collins and Evans' point of view, as long as one of the doctors has or develops interactional expertise into the other medical field, in order to be able to make informed decisions about the therapeutic approaches based on relevant insights from both medical fields. While in this example, the two contributory experts need to solve a common problem, Collins and Evans (2002) also give examples of situations where interactional expertise is developed by experts to address their own specific goals. For instance, they often invoke sociologists, who need to become fluent in the practice language of the scientific group they study, to be able to successfully conduct a sociological analysis. In such cases, however, Collins and Evans (2002; 2017) conceive of the development of interactional expertise as the responsibility of the group doing the study or needing to solve a specific problem, that is why only the contour of the arrow in Figure 4.1 is marked.

Figure 4.1 The development of interactional expertise under conditions of symmetry



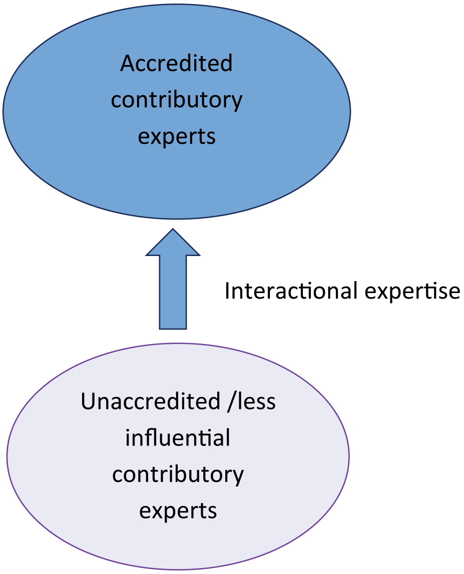
Collins and Evans (2002) tie the development of interactional expertise under conditions of asymmetry to instances when interactional expertise is needed to facilitate the integration of a certain (sub)type of contributory expertise into another, broader, form of contributory expertise, with which the first is continuous, for the satisfactory resolution of a complex problem. They give examples both of situations when third parties are involved as well as of instances when the integration of the one type of expertise into the other occurs without external involvement. In the first case, Collins and Evans (2002) mention that such absorption may be mediated by people who are not contributory experts in any of the two fields, but who hold interactional expertise in both, as depicted in Figure 4.2. For instance, a sociologist may translate the knowledge and perspectives of a (smaller) group of unaccredited and less influential experts into a language that the accredited experts can understand, in order to appreciate and be able to use the insights of the unaccredited experts to solve a common problem.

Figure 4.2 Absorption of knowledge among contributory experts in different, yet relevant fields with the assistance of interactional experts



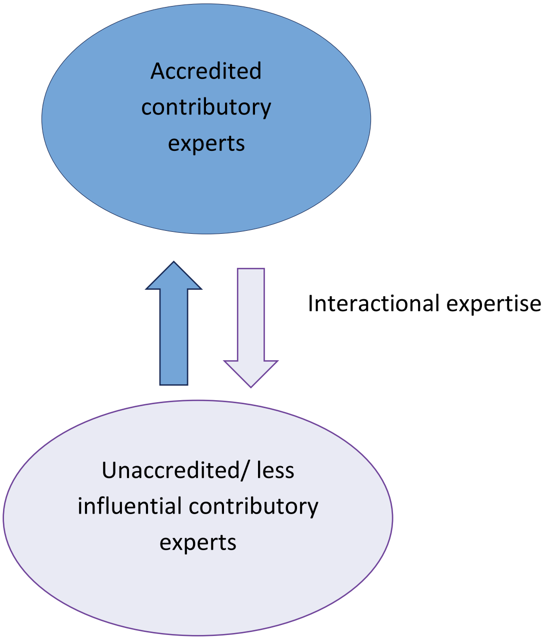
When discussing the development of interactional expertise under conditions of asymmetry, Collins and Evans (2002) tend, however, to ascribe the task or capability of acquiring interactional expertise to the group of experts which are better positioned to solve a certain problem because of the epistemic authority, legitimacy, and other resources they already enjoy, as Figure 4.3 below indicates. Thus, they provide a new reading of Wynne's (1996) study on the relationship between scientists and the Cumbrian farmers in the aftermath of the Cernobyl disaster, where the scientists failed to recognize the contributory expertise of the farmers, who lacked official accreditation. Collins and Evans (2002:255) state that for the farmers' insights to be taken seriously, the latter "would *not* have had to engage in a symmetrical conversation" (emphasis in the original), but the scientists would have had to be willing to incorporate the former's insights by developing the relevant interactional expertise. Another example testifying to the same perspective is that of medical professionals becoming interactional experts on the lived experiences of their patients, that Collins and colleagues (2017) more recently invoked and which was already mentioned in section 5. Importantly, in Collins and Evans' (2002:256) view, "only the party with interactional expertise can take responsibility for combining the [contributory] expertises".

Figure 4.3 The development of interactional expertise under conditions of asymmetry without the involvement of a third party



This argument suggests that under conditions of asymmetry, Collins and Evans believe the more influential party has the necessary resources to develop interactional expertise. I argue, however, that interactional expertise can not only develop in a bottom-up direction, whereby stakeholders who already enjoy epistemic authority in a given field expand their expertise by absorbing knowledge from unofficially-recognized contributory experts in a (sub)field of interest, but it can also be acquired in what may seem like a top-down manner. Thus, people who have contributory expertise in a field but are not officially accredited can become fluent in the practice language of relevant epistemic groups, if they are endowed with other necessary resources. The acquisition of interactional expertise might this way contribute towards the development of more symmetric relationships between people who enjoy different standing due to the status of the field in which they have contributory expertise, as Figure 4.4 shows.

Figure 4.4 The bi-directional development of interactional expertise under conditions of asymmetry



As the description below will show, even under conditions of asymmetry, people endowed with interactional expertise can engage in exchanges that are more substantial than having interesting conversations with contributory experts, as Collins and Evans (2002) believe. Furthermore, whereas in determining the (a)symmetric character of an interaction, Collins and Evans seem to focus mainly on epistemic standing and authority as the determining factors, I argue that the availability of other resources may help balance such exchanges. More attention should therefore be paid to the type and quality of the interactions between interactional and contributory experts in different fields and to how different conditions or types of asymmetry may affect them. The exchanges of the bloggers studied here are revelatory in this sense.

In their interactions with bipolar patients, Tracy and Fast go beyond the mere provision and explanation of medical information, and often position themselves as complements or alternatives to medical professionals. The bloggers achieve this by combining knowledge with care, by expressing concern for the realities of their readers' lives. They try to locate for them institutions that might be of help, they explain how to apply for social provisions, and express empathy towards the difficult choices people face in relation with bipolar disorder and its treatment. The bloggers also give practical advice, stemming from their experiential knowledge: "Freeze your fish oil pills! This makes them a lot easier to digest. I take mine right before bed." (Fast, September 22, 2008). Furthermore, they give suggestions on how to behave when interacting with medical professionals, on how to meditate, or prepare for stressful events, such as holidays or Christmas. Tracy and Fast also mediate between people diagnosed and their loved ones, shedding light upon some of the former's behaviors and advocating for particular approaches in their interactions. The bloggers show thus their substantial knowledge while remaining relatable, and readers often express gratitude for the information they provide, as this quote indicates: "Natasha. ….This is your blog and a very good one at that.. You have always shown to be a very smart, caring and genuine individual". (*Michael,* December 9, 2013) Thus, many readers seek the counsel of this new type of stakeholder because they are convinced of their expertise and because they trust them. While the bloggers acknowledge the authority of mental health specialists and display substantial medical knowledge to render their views credible, they try to steer away from the controversy and suspicion which regularly surround the recommendations of medical professionals who receive honoraria from pharmaceutical companies. Such tactics are in line with those observed by scholars among "A-list" political bloggers, who sought to increase their authority by professing their independence from the establishment, i.e. "big media", while taking up some of their activities and professional values (Park, 2009).

One of the challenges encountered by researchers interested in collaborating with patients is to enable their contributions (Hewlett et al, 2006). This is another area where online expert mediators engage in mediation work, as they succeed to enhance the cathetic dimension Borkman (1976) referred to, and develop a space where their readers can articulate their experiences and negotiate how they position themselves in relation to their condition and the medical community. The bloggers educate people diagnosed about medical terminology and perspectives, so that the latter are better able to engage in collaborative projects with researchers. This is important, because not all bipolar patients may have the time and health condition necessary to grapple with medical terminology and research methodology. Moreover, Tracy and Fast may provide people diagnosed with the confidence that the insights they have are relevant and valuable, thus enabling them to interact with medical professionals with the assurance and determination necessary to move towards more equal exchanges. They may also help those interested in research participation to develop the patience and distance necessary to accept results which may contradict their personal views.

Next to bipolar patients, the bloggers have constituted themselves as valuable allies for medical professionals who lack but need their insights derived from the lived experience with this condition for various aims. Thus, online expert mediators can assist medical professionals to acquire interactional expertise regarding the embodied experience of bipolar disorder, and thus help them develop a broader perspective about this condition and novel research ideas. By positioning themselves as representatives of their bipolar readers, the bloggers provide medical professionals with important information regarding the research directions bipolar patients would find relevant. In a context where medical expertise continues to be challenged, online expert mediators further serve the interests of the medical community, by bestowing additional credibility upon the scientific approaches they champion.

The bloggers have also acquired sufficient medical knowledge and other relevant resources for medical professionals to want to collaborate with them. For instance, together with Prakash Masand, M.D., Tracy wrote an article published in 2014 in the medical journal *The Primary Care Companion for CNS Disorders*. Furthermore, in July 2016 she initiated a survey about patients' experiences concerning electroconvulsive therapy (ECT) on her personal blog:

> My name is Natasha Tracy and this ECT survey was my idea. I am running this survey with Dr. Prakash Masand [hyperlink provided], the psychiatrist behind the site Global Medical Education [hyperlink provided] which aims to educate others, particularly doctors, about medical issues such as those surrounding mental illness.
>
> For my part, I have bipolar disorder and have had ECT for bipolar depression. This has made me passionate about the subject as I see the extreme debate that goes on about this treatment online. (Tracy, Bipolar Burble, July 3, 2016)

This quote emphasizes Tracy's claims to expertise —experiential but also informed by knowledge acquired online— and the complementary role she ascribes to medical professionals in the practices she takes up. While she is knowledgeable enough to come up with this idea and for an authoritative medical figure to collaborate with her, Tracy needs this partnership to legitimate her endeavor, since she lacks the apparently still necessary official accreditations. Tracy's position as an influential blogger enables her to collect quickly and cheaply data from many readers, which her medical collaborator can then use in order to produce further knowledge. Moreover, Tracy's expertise about bipolar disorder has been publicly acknowledged by medical professionals. For instance, Ronald Pies, M.D., wrote about her:

> As a specialist in bipolar disorders, I can say that Natasha's understanding of this illness is more accurate and sophisticated than that of many physicians I have encountered over the past 30 years. But more than that: she shows uncommon wisdom and deep compassion, when it comes to discussing psychiatrists and psychiatry. (Pies, Psychiatric Times, May 24, 2012).

Reputed medical professionals have also collaborated with Fast. For instance, she co-authored the books *Take Charge of Bipolar Disorder: A 4-Step Plan for You and Your Loved Ones to Manage the Illness and Create Lasting Stability* (2004), *Loving Someone With Bipolar Disorder* (2004) and *Get It Done When You're Depressed* (2008) together with Dr. John Preston. He is now professor emeritus with Alliant International University in Sacramento, the author of 21 books, and the recipient of the "President's Award" from the Mental Health Association and of "Distinguished Contributions to Psychology Award" from the California Psychological Association. Like Tracy, Fast has also used her blog to encourage people to participate in studies she champions:

> Can We Diagnose Bipolar Disorder Using Eye Images? (…)
>
> This is the question a new study from Souther [sic] Methodist University poses based off of my work on recognizing signs of mania in the eyes. Please visit the website and read more about this potently life changing study. What if we could see that we are manic through a physical sign even when our brain is telling us we are just fine? Think of the possibilities.
>
> Click here to read more about the SMU Mania in the Eyes Research Study. [hyperlink provided]
>
> If you love my work, I would love your support of this project. Even one picture helps! (Fast, Bipolar Happens!, September 27, 2017)

This quote reveals the substantial involvement and medical knowledge Fast has acquired, as it implies that scientists found her hypothesis worthy not only of consideration, but also of developing a study to test it. The excerpt is also important because it shows again that one of the ways in which this new type of stakeholder can make themselves interesting for medical professionals to want to collaborate with them is by using their popularity among people diagnosed with bipolar disorder to encourage them to provide the data scientists need for research. The last paragraph suggests that Fast conceives of her relationship with her readers as a reciprocal one, where she shares her experiences and medical insights into an accessible vocabulary, and expects them to participate in certain studies in return, as a way of expressing their appreciation for her activities. Furthermore, Fast is claimed to "train pharmacists, psychiatric residents, social workers, alternative health care practitioners, general physicians, nurse practitioners, therapists and many more health care professionals on the topics of depression and bipolar disorder management." (Amazon, 2016). Thus, both Fast and Tracy as well as the medical professionals they work with profit from forging alliances, and such substantial exchanges are characteristic for the activities of online expert mediators.

The power and legitimacy the bloggers acquire through collaboration with medical professionals are subsequently used by Tracy and Fast to engage even more substantially in research practices. For instance, Fast ventured in the production of medically-relevant knowledge on her own, developing *The Health Cards Treatment System for Bipolar Disorder*, which "works with or without medications", as she claims (Bipolar Happens!, 2016). This system is meant both for bipolar patients and family members, and Fast states it is very successful: "I know that tens of thousands of my readers use the Health Cards daily… (…) Even my health care professionals use them!" (Fast, Bipolar Happens!, May 6, 2010). Apart from legitimating her invention, such claims show that there are areas where medical professionals can learn from her. While using Fast's cards attests to an awareness by medical professionals that bipolar patients and their families may have needs that traditional medical approaches insufficiently address, it may also be a means for them to retain monopoly over medical knowledge at a time when other professionals challenge it.

These bloggers are thus more than interesting and inspiring conversation partners for medical professionals. They are stakeholders that researchers want to collaborate with substantially, as they can facilitate the enrolment of a high number of study participants, they can provide experiential knowledge and important insights into relevant areas for future research. The way for such partnerships has already been paved by patient organizations, but there have also been several substantial collaborations between researchers and particular individuals. Notable in this sense are the research activities of Portia Iversen (Iversen, 2007) and Sharon Terry (Terry & Boyd, 2001), who have directly contributed to the development of new therapeutic approaches for autism, and to the identification of the gene mutation causing Pseudoxanthoma Elasticum (PXE), respectively. Yet, whereas Iversen and Terry disposed of important resources as the leaders of two influential patient groups and were not themselves diagnosed with the conditions they studied, Tracy and Fast are bipolar patients and have managed to acquire the resources mentioned above individually, through their skillful use of the internet.

4.7.2 Interactional expertise and the use of a specific medium

In their conceptualization of interactional expertise, Collins and Evans do not consider the effects of the medium through which interactional expertise is displayed. I expand this notion by showing that the internet has importantly shaped how Tracy and Fast have enacted their interactional expertise. Studying how the internet shapes the enactment of interactional expertise is particularly important, since "in the context of the digital shift, the demarcation between certified experts and lay people is blurring" (Dickel & Franzen, 2016:3). This topic has generated a lot of interest among scholars in the field of studies in science education and science communication, who have studied how the public responds to or engages with scientific knowledge provided via different media. Important in this sense is the study conducted by Shanahan (2010) on how scientific and personal expertise about health were expressed and discussed in the online comment section of a newspaper. Her study showed that even in peer-to-peer interactions, the most appreciated comments were those of contributors who claimed (some level of) scientific rather than personal expertise. Even though the online exchanges between the blog authors studied here and their readers may be conceived as peer-to-peer interactions due to the shared diagnosis of bipolar disorder and certain embodied experiences, there are important differences that need to be considered. Unlike the contributors scrutinized by Shanahan (2010), the bloggers I study are individuals with a well-established public persona, who have to further demonstrate the interactional expertise displayed in their posts by (not) engaging with their readers' comments. While their audience may include contributory and interactional experts, an important difference from Shanahan is that such exchanges already take place in conditions of inequality, since as authors and owners, the bloggers speak to their readers, as Fast's quote above indicates. Shanahan's findings are nevertheless relevant, showing that online scientific expertise is not determined based on the invocation of credentials, but on one's ability to take up scientific practices, such as the provision of evidence and the citation of relevant sources, thereby revealing one's familiarity with the scientific norms and culture.

Such approaches are also adopted by Tracy and Fast as means to articulate and reinforce their online standing. For instance, comments from readers are used as opportunities to display their expertise by giving additional medical information and by correctly identifying specific interventions. Since people with experiential expertise display growing tendencies towards scientization in their contributions (Shanahan, 2010), these bloggers do not merely invoke scientific claims, but carefully select, apply, and interpret them. This is how Tracy reacts to a vague comment about a new test meant to determine the effectiveness of medical treatments for bipolar disorder: "I believe you're talking about the cytochrome P450 (CYP450) tests which I know are offered at the Mayo Clinic. (Also used in cancer treatment)". (Tracy, Breaking Bipolar, November 5, 2012) Thus, apart from having sufficient knowledge to understand what the contributor is referring to, Tracy also contextualizes the test, linking it to other medical disciplines. The bloggers further use their readers' comments as indicative of their informational needs and as sources of inspiration for some of their posts. From this perspective, comments help bloggers retain their popularity and influence by addressing topical issues.

Yet, the internet also poses challenges to the display of interactional expertise, as the information they provide is open to the scrutiny of people with different levels of education, different views, and at different moments in time. To become and remain credible mediators, Tracy and Fast therefore need to show that the knowledge they share is authoritative while staying open to different perspectives. One way in which they manage such contradictory expectations is by using the internet's multiplicity, giving different nuances to their messages on different platforms. They further use the asynchronous and selective character of comment exchanges to react advantageously to their readers' unexpected questions or reactions. Since Tracy and Fast are at liberty to choose when they react to comments, they can take the time to acquire more information or to work on a reply until it has a satisfactory shape. In the meantime, other readers may come to their "help", by sharing their knowledge and experiences. Their successful display of interactional expertise is also informed by the wise selection of instances when they interact with their readers. Thus, while they choose to intervene in situations where their knowledge, empathy, and relatability are emphasized, they remain silent in front of provocations which may alienate their audiences. Comment rules are another important instrument through which the bloggers may contain their readers' challenges and avoid controversy. For instance, initially Tracy did not allow commentators to provide the exact names and dosage combination of medicines. While this approach was meant to prevent readers from trying medicines without medical approval, it also weakened the epistemic claims and challenges they could bring against her.

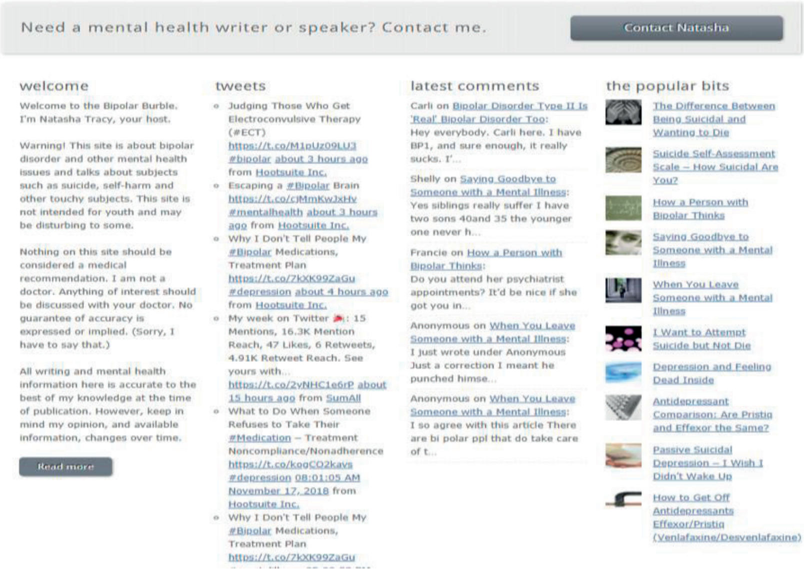
The technology of blogs also enables Tracy and Fast to display their interactional expertise using images and hyperlinks. Their blog entries are often accompanied by images which either illustrate the main message of the post or bring an additional dimension to the information provided in writing. Depending on the topic, the bloggers choose for different ratios between written material and images. For instance, when discussing alternative ways of ensuring mood stability, Fast only writes a few lines but provides numerous images depicting relaxing activities. When the effects of particular medications are discussed, however, the written text dominates. At the same time, both bloggers provide videos of themselves on the blog, where they talk about certain experiences or advise their audiences. While it may be that their use of videos is informed by curiosity and by the desire to experiment with new technologies and opportunities available to update their blogs, such videos also serve to enhance the authenticity of their accounts, and to strengthen the bond between themselves and their readers. Through the use of video, the person behind the text of many posts, books, magazine articles becomes a three-dimensional being, who moves and talks in particular ways, whose appearance may reveal the presence of bipolar disorder or may be the embodiment of its successful management.

Hyperlinks reveal important alliances as well as power relations. Both bloggers use them in order to show that the information they provide is based on reliable sources.

They refer mainly to articles available in medical databases such as PubMed and Medscape or to posts by medical professionals on platforms where they collaborate. Tracy and Fast thus position themselves as trustworthy mediators between reliable sources of medical knowledge and interested audiences. Hyperlinks are also used by bloggers to emphasize their vast body of work. For instance, Tracy uses them to direct readers to her older posts. Interestingly, the bloggers generally refrain from using these affordances to share knowledge produced by other people lacking accreditations or to introduce their readers to projects initiated by "citizen scientists". This indicates that the high standing these bloggers enjoy is not due to a subversive use of the internet, but rather to their alliances with powerful stakeholders.

It is important to note that there are also significant differences between the ways in which Tracy and Fast use the internet. Tracy's blog is highly interactive, having posts which acquire hundreds of comments, and she uses integrated approaches to increase the visibility of new posts. Thus, Tracy often uses Twitter and Facebook to notify readers about news on her blog, while Twitter updates are provided on her blog's main page. That interactivity is very important to her can also be derived from the fact that very popular blog posts and the posts with the most recent reactions are also listed on the first page, as you can see in Figure 4.5, thereby guiding visitors on her page and encouraging them to engage in specific actions.

Figure 4.5 Fragment from the first page of Natasha Tracy's blog, *Bipolar Burble*. Retrieved on January 8, 2019.



Need a mental health writer or speaker? Contact me.

welcome

Welcome to the Bipolar Burble. I'm Natasha Tracy, your host.

Warning! This site is about bipolar disorder and other mental health issues and talks about subjects such as suicide, self-harm and other touchy subjects. This site is not intended for youth and may be disturbing to some.

Nothing on this site should be considered a medical recommendation. I am not a doctor. Anything of interest should be discussed with your doctor. No guarantee of accuracy is expressed or implied. (Sorry, I have to say that.)

All writing and mental health information here is accurate to the best of my knowledge at the time of publication. However, keep in mind my opinion, and available information, changes over time.

tweets

- Judging Those Who Get Electroconvulsive Therapy (#ECT) https://t.co/M1pUz09LU3 #bipolar about 3 hours ago from Hootsuite Inc.
- Escaping a #Bipolar Brain https://t.co/cJMmKwJxHv #mentalhealth about 3 hours ago from Hootsuite Inc.
- Why I Don't Tell People My #Bipolar Medications, Treatment Plan https://t.co/7kXK99ZaGu #depression about 4 hours ago from Hootsuite Inc.
- My week on Twitter: 15 Mentions, 16.3K Mention Reach, 47 Likes, 6 Retweets, 4.91K Retweet Reach. See yours with… https://t.co/2yNHC1e6rP about 15 hours ago from SumAll
- What to Do When Someone Refuses to Take Their #Medication – Treatment Noncompliance/Nonadherence https://t.co/koqCO2kays #depression 08:01:05 AM November 17, 2018 from Hootsuite Inc.
- Why I Don't Tell People My #Bipolar Medications, Treatment Plan https://t.co/7kXK99ZaGu

latest comments

Carli on Bipolar Disorder Type II Is 'Real' Bipolar Disorder Too:
Hey everybody. Carli here. I have BP1, and sure enough, it really sucks. I'…

Shelly on Saying Goodbye to Someone with a Mental Illness:
Yes siblings really suffer I have two sons 40and 35 the younger one never h…

Francie on How a Person with Bipolar Thinks:
Do you attend her psychiatrist appointments? It'd be nice if she got you in…

Anonymous on When You Leave Someone with a Mental Illness:
I just wrote under Anonymous Just a correction I meant he punched himse…

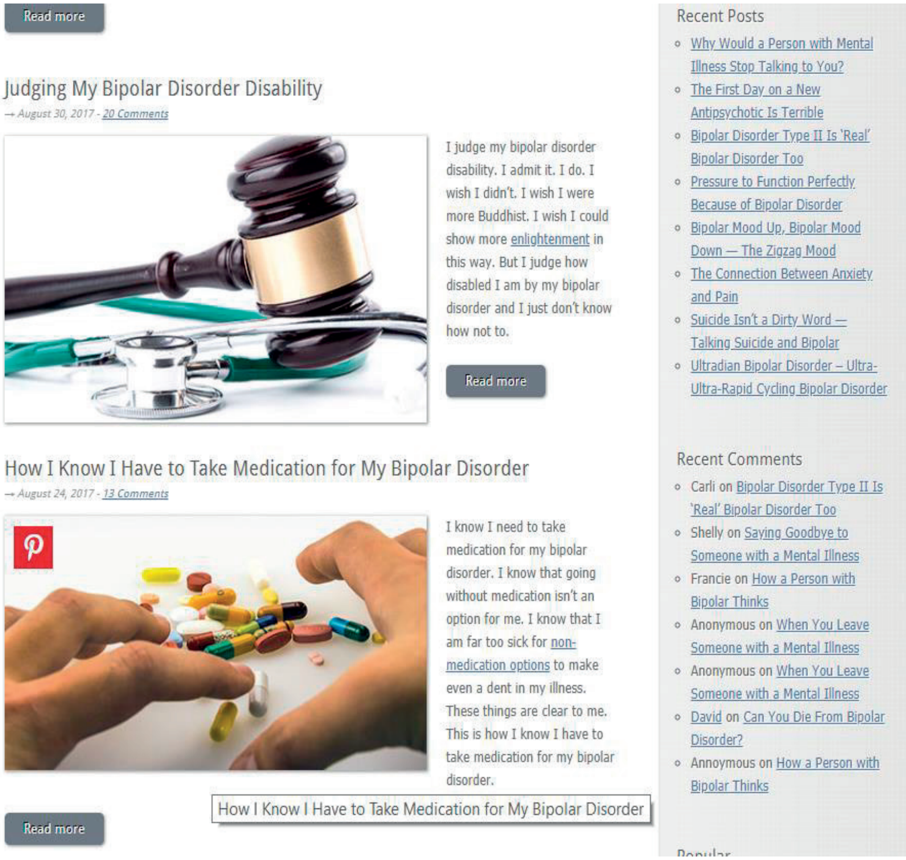
Anonymous on When You Leave Someone with a Mental Illness:
I so agree with this article There are bi polar ppl that do take care of t…

the popular bits

- The Difference Between Being Suicidal and Wanting to Die
- Suicide Self-Assessment Scale – How Suicidal Are You?
- How a Person with Bipolar Thinks
- Saying Goodbye to Someone with a Mental Illness
- When You Leave Someone with a Mental Illness
- I Want to Attempt Suicide but Not Die
- Depression and Feeling Dead Inside
- Antidepressant Comparison: Are Pristiq and Effexor the Same?
- Passive Suicidal Depression – I Wish I Didn't Wake Up
- How to Get Off Antidepressants Effexor/Pristiq (Venlafaxine/Desvenlafaxine)

On Tracy's blog, the number of comments each post acquires is listed below the title and a hyperlink is provided, so that interested readers can directly access them rather than read the post (Figure 4.6). The hyperlink also draws attention to the comments visually, since it is provided in blue whereas the remainder of the information provided about a specific post is typed in black.

Figure 4.6 Fragment from the overview of blog posts on Natasha Tracy's blog, *Bipolar Burble*. Retrieved on October 3, 2017.



Judging My Bipolar Disorder Disability

→ August 30, 2017 - 20 Comments

I judge my bipolar disorder disability. I admit it. I do. I wish I didn't. I wish I were more Buddhist. I wish I could show more enlightenment in this way. But I judge how disabled I am by my bipolar disorder and I just don't know how not to.

How I Know I Have to Take Medication for My Bipolar Disorder

→ August 24, 2017 - 13 Comments

I know I need to take medication for my bipolar disorder. I know that going without medication isn't an option for me. I know that I am far too sick for non-medication options to make even a dent in my illness. These things are clear to me. This is how I know I have to take medication for my bipolar disorder.

How I Know I Have to Take Medication for My Bipolar Disorder

Recent Posts

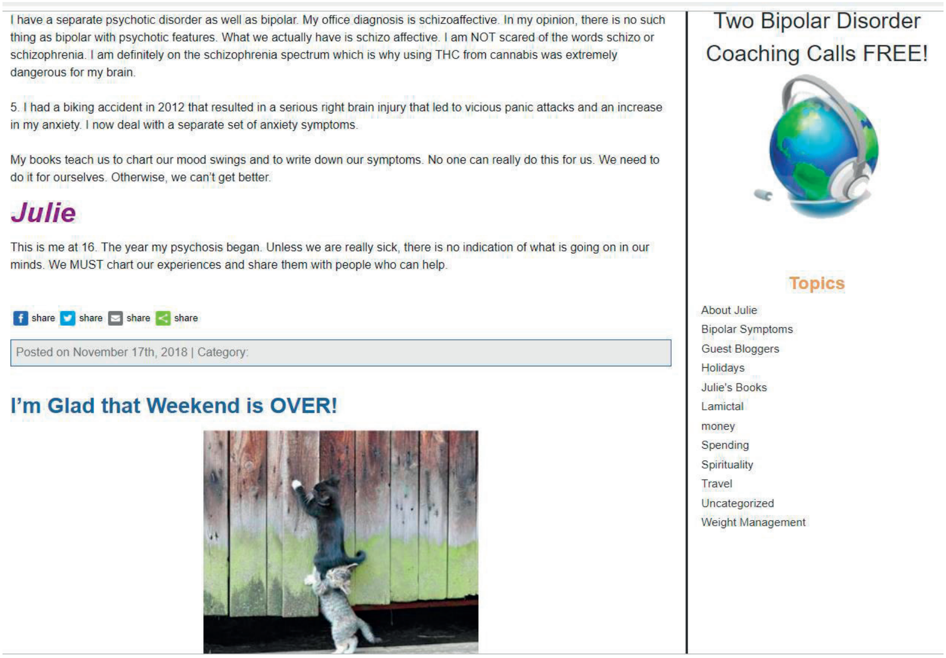
- Why Would a Person with Mental Illness Stop Talking to You?
- The First Day on a New Antipsychotic Is Terrible
- Bipolar Disorder Type II Is 'Real' Bipolar Disorder Too
- Pressure to Function Perfectly Because of Bipolar Disorder
- Bipolar Mood Up, Bipolar Mood Down — The Zigzag Mood
- The Connection Between Anxiety and Pain
- Suicide Isn't a Dirty Word — Talking Suicide and Bipolar
- Ultradian Bipolar Disorder – Ultra-Ultra-Rapid Cycling Bipolar Disorder

Recent Comments

- Carli on Bipolar Disorder Type II Is 'Real' Bipolar Disorder Too
- Shelly on Saying Goodbye to Someone with a Mental Illness
- Francie on How a Person with Bipolar Thinks
- Anonymous on When You Leave Someone with a Mental Illness
- Anonymous on When You Leave Someone with a Mental Illness
- David on Can You Die From Bipolar Disorder?
- Anonymous on How a Person with Bipolar Thinks

In contrast, Fast is more focused on sharing insights and providing varied information to her readers rather than encouraging online contributions on her blog. Thus, the blog posts are organized vertically, with the most recent ones at the top, and there is a small number of keywords provided on a side bar, through which users can identify specific posts, as Figure 4.7 indicates.

Figure 4.7 Fragment from the blog posts overview on Julie A. Fast's blog, *Bipolar Happens!* Retrieved on November 5, 2018.



I have a separate psychotic disorder as well as bipolar. My office diagnosis is schizoaffective. In my opinion, there is no such thing as bipolar with psychotic features. What we actually have is schizo affective. I am NOT scared of the words schizo or schizophrenia. I am definitely on the schizophrenia spectrum which is why using THC from cannabis was extremely dangerous for my brain.

5. I had a biking accident in 2012 that resulted in a serious right brain injury that led to vicious panic attacks and an increase in my anxiety. I now deal with a separate set of anxiety symptoms.

My books teach us to chart our mood swings and to write down our symptoms. No one can really do this for us. We need to do it for ourselves. Otherwise, we can't get better.

Julie

This is me at 16. The year my psychosis began. Unless we are really sick, there is no indication of what is going on in our minds. We MUST chart our experiences and share them with people who can help.

Posted on November 17th, 2018 | Category:

I'm Glad that Weekend is OVER!

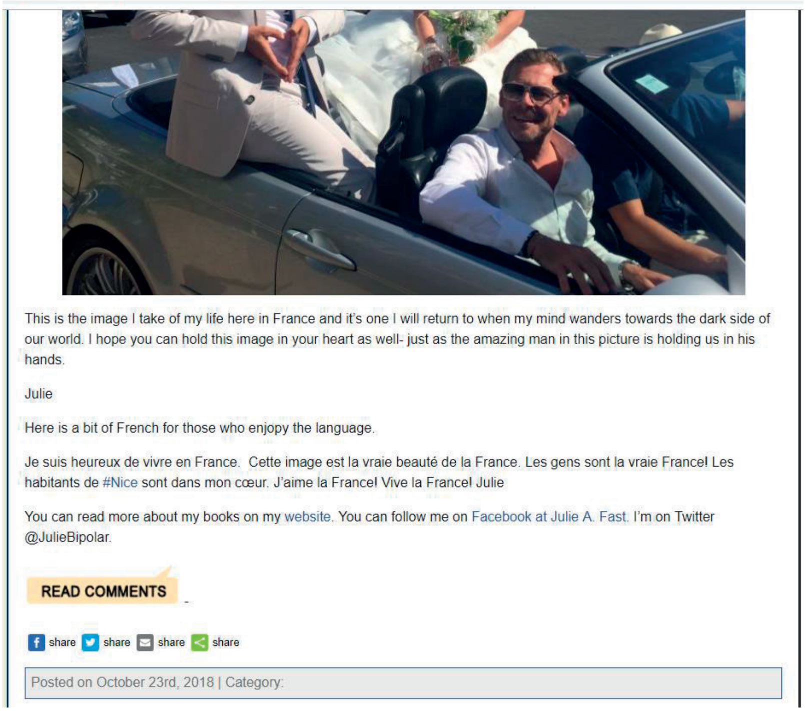
Two Bipolar Disorder Coaching Calls FREE!

Topics

- About Julie
- Bipolar Symptoms
- Guest Bloggers
- Holidays
- Julie's Books
- Lamictal
- money
- Spending
- Spirituality
- Travel
- Uncategorized
- Weight Management

The number of comments available for the posts is not directly visible, but readers need to press an additional button to see them (Figure 4.8), and the comment function is not available for all posts. Unlike Tracy, her posts generally receive a small number of comments, yet her blog continues to be voted among the best bipolar blogs currently available. To a certain extent, the limited interactivity on Fast's blog may be due to the fact that it developed as a continuation of a newsletter, so she may be accustomed to use the blog mainly to share information. Since many of her blog posts contain hyperlinks to her contributions on the online forum of bp Magazine, it may be that Fast prefers to have only one designated platform at a time for online interactions and that she has ascribed this function to the forum. It may also be the case that she prefers personal correspondence with her readers, since she mentioned answering hundreds of letters per week at the time when she had just started circulating her newsletter, a habit which she may have preserved.

Figure 4.8 Fragment from Julie A. Fast's blog, *Bipolar Happens!* Retrieved on November 5, 2018.



This is the image I take of my life here in France and it's one I will return to when my mind wanders towards the dark side of our world. I hope you can hold this image in your heart as well- just as the amazing man in this picture is holding us in his hands.

Julie

Here is a bit of French for those who enjoy the language.

Je suis heureux de vivre en France. Cette image est la vraie beauté de la France. Les gens sont la vraie France! Les habitants de #Nice sont dans mon cœur. J'aime la France! Vive la France! Julie

You can read more about my books on my website. You can follow me on Facebook at Julie A. Fast. I'm on Twitter @JulieBipolar.

Posted on October 23rd, 2018 | Category:

In general, both bloggers adapt the combination of medical and experiential knowledge, so that it is in line with the type of platform they contribute on, they react to comments strategically, and are very careful in their use of hyperlinks. Thus, their display of interactional expertise is importantly shaped by their use of blog affordances.

4.8 Discussion

The bloggers discussed here can be seen as a particular and highly successful form of entrepreneurial selves (Petersen & Lupton, 1996). While this new type of stakeholder — online expert mediators — may fulfill a complementary or additional function to social movements, it also represents a move away from them and a focus upon exceptional patient figures, who have been able to use various resources and the opportunities and limitations the internet has made available to become highly influential. This stakeholder category emerges thus at the intersection between a (mental) health condition, the acquisition of particular types of knowledge, and the use of a specific medium. By combining personal experiences with medical knowledge, Tracy and Fast have gone beyond the average illness blog, where one's personal experiences are conveyed in an intimate, diary-like fashion, and have come closer to issue-based blogs, where different types of information considered relevant about a particular topic are provided and discussed using arguments and multiple perspectives (O'Neil, 2005). The interactional expertise that they develop and articulate to various degrees has a strong bi-directionality, as they need to be fluent in the language of medical knowledge on bipolar disorder as well as to retain their experiential knowledge in a format which allows them to relate to readers diagnosed with bipolar disorder and their families. Thus, in their acquisition and articulation of interactional expertise, online expert mediators are reminiscent of journalists, who "develop different degrees of bipolar "interactional expertise", specializing in interactions with their sources on the one hand and audiences on the other" (Reich, 2012:339). Furthermore, the online and offline activities of these bloggers foreground the importance of focusing on the multiple shifting identities that stakeholders can call upon in their development and enactment of expertise. Their highly influential position was achieved through their ability to skillfully switch between their identity as individuals diagnosed with bipolar disorder, as successful blog owners, as representatives of many people diagnosed with bipolar disorder, etc. I have taken up these insights in the conceptualization of expertise I put forward, where expertise is approached as a practical achievement realized through coordination and affective labor among stakeholders who occupy multiple and shifting positions within a complex ecosystem.

The rise of these stakeholders takes place in a context in which the informational and health imperatives require people to assume responsibility about their health (Kivits, 2013), yet the difficulties of living with a particular condition may lead them to prefer to follow someone else's lead (Lemire et al, 2008). Since the expertise of medical professionals has been challenged over the last decades, many people diagnosed may seek to resolve this tension by following the advice of this new stakeholder type, by using such expert bloggers as arbiters. At the same time, the rise of this new stakeholder is also due to patients and their families requiring, apart from medical information, also encouragement and guidance. Nevertheless, these new stakeholders are also confronted with suspicion given the varying quality of the health information available online and the growing awareness that many public speakers and opinion-setters represent particular groups of interest. To be successful, online expert mediators therefore need to convince their readers to develop different types of trust: they must trust the bloggers; they must trust certain online spaces or platforms; they must trust (at least) the branches of science the bloggers themselves rely upon (Harris et al, 2011).This also shows that the type of expertise these new stakeholders have acquired and enact online is a practical achievement, which they have realized by moving back and forth between relevant groups within the particular healthcare ecosystem in which they operate, by choosing to highlight particular aspects of their identity depending on the context and their goals, and by being caring but also careful towards other people and other types of knowledge.

Importantly, this chapter has indicated that the medium plays an important role in how interactional expertise is displayed, thereby extending Collins and Evans' conceptualization of this notion. In so doing, it has also brought into relief some problematic aspects concerning the development of this new stakeholder category. While interactional expertise is necessary for this new type of stakeholdership, a strong medium is also needed. Developing interactional expertise has enabled Tracy and Fast to gain access and to develop close contacts with medical professionals, yet it is their online popularity which has provided them with the resources necessary to engage in substantial exchanges with the latter. The internet has therefore allowed them to convincingly position themselves in their relations with medical scientists as representatives of people diagnosed with bipolar disorder in a way which is reminiscent of the approach taken up by the American AIDS activists described by Epstein (1996). Epstein problematized the position "lay experts" occupy in relation to the "lay lay", highlighting that the acquisition of competence into a new type of knowledge impacts how one understands and relates to the other types of knowledge with which one is endowed as well as on one's relations to others. Thus, he argued that by "learning the language and culture of medical science" (Epstein, 1995:417) people diagnosed risk distancing themselves from other people diagnosed with the same condition, from their views and interests. From this perspective, the close collaborations the bloggers develop with medical professionals may lead to a further obfuscation of the differences in experience as well as in interests, needs, and values existing between people diagnosed with bipolar disorder (Rowland et al, 2017), who follow these bloggers online.

While blogs have been acknowledged as technologies with a democratizing potential (Huovila & Saikkonen, 2016), the findings presented here show that online expert mediators acquire such high standing by developing close ties with "traditional" experts. Thus, rather than contributing to opening the field of scientific knowledge production to more people who lack official credentials, online expert mediators might inadvertently contribute to the refinement of existing hierarchies in the relations between medical professionals and patients. From this perspective, it is regrettable that the interactions between these bloggers and medical professionals occur most of the time offline or through private communication, so that it is not possible to observe how they negotiate participation in various projects and support for various initiatives. Since the bloggers' interactional expertise is limited to particular areas of medical knowledge on bipolar disorder and does not exclude personal preferences, online expert mediators also risk presenting their readers a skewed perspective on the use and effectiveness of the currently available forms of treatment. Another danger stems from the mediation work online expert mediators engage in between family members, as they may end up certifying particular symptoms and behaviors, with which they are acquainted, while casting doubt upon the authenticity of those they are not familiar with.

The online expert mediators studied here creatively combined their personal insights about bipolar disorder with medical knowledge in their online contributions. In so doing, they not only selected and adapted the medical knowledge they were familiar with to best serve their purposes, but they also translated it into a more accessible vocabulary for people less familiar with medical terminology. Through such actions, they may help bridge the digital divide when it comes to medical literacy by sharing medical knowledge in an accessible manner, by making people diagnosed and their families aware of the options at their disposal, and by helping them get in touch with support groups and other organizations. Some people diagnosed with other mental health conditions, such as autism and schizophrenia, have used the internet to legitimate their claims by arguing that their personal experiences should be understood as different ways of being in the world rather than as pathological behaviors (Ringer & Holen, 2016; Crossley, 2006). Unlike them, the online expert mediators discussed here legitimated their claims using medical knowledge. Having achieved a highly influential position, in the future they might harness their creativity and various skills to contribute in novel ways to the proliferation and diversification of collaborations between people diagnosed and medical professionals.

Ironically, whereas Fast started her online career after she moved to France, no French online bloggers enjoying similar standing to her and Tracy were identified. Since the use of the internet for mental health related purposes has been promoted by French authorities, as chapter 2 has indicated, and since many people living in France have access to the internet, this is a rather puzzling finding. It is all the more surprising since the results described in chapter 3 revealed that French online contributors were supporters of active forms of patienthood, and tried to actively manage their condition and to contribute to new knowledge about treatment effectiveness. The absence of this new type of stakeholder in France might be linked to particular social and cultural elements which shape the use of the internet and the ways in which people relate to their condition. While numerous French blogs on bipolar disorder could be identified, they were either read by few people or they had a very limited interactive character, receiving five comments or less for most posts. There were also blogs on bipolar disorder which enjoyed greater visibility, as they were authored occasionally on the online platforms of reputed French newspapers, such as *L'Avventura*, a caricature-based blog authored by Fiamma Luzzati for *Le Monde*, or *La Vie d'un Bipolaire*, authored by W. on the website of *L'Express*. Nevertheless, even in these cases, the level of interactivity was low. This might be informed by specific French cultural understandings and approaches to blogs, which conceive of them as online spaces where different types of information can be shared in a concise manner rather than as interactive platforms. This view is supported by the fact that even when famous medical professionals decided to share their views on blogs, these were not accompanied by a comment function. The fact that such medical professionals had become famous through their activities on radio and television suggests that rather than using the internet to become influential, in France people use it as an additional medium, to reach more audiences or to convey the image of someone who is also up-to-date regarding online technologies.

Another explanation is that the absence of such influential individuals diagnosed with bipolar disorder or with any other condition, for that matter, may be due to the fact that the imperative for people to become active patients and assume responsibility for their health led in France to the development of entrepreneurial subjectivities that manifest themselves differently. An example in this sense is *Bipote*, the administrator and founder of *Le Forum des Bipotes* (LFB), mentioned in the previous chapter, who was diagnosed with bipolar disorder himself. Even though as forum administrator he had significant power and control, his position there was not as prominent and as influential as that of the bloggers studied here, despite his substantial knowledge about bipolar disorder. His preference for a forum rather than a blog may denote a preference for collective enterprises rather than individual approaches, and it may be that more people in France share this attitude.

The lack of this new type of stakeholder in the French landscape may also be informed by the fact that patient associations remain highly influential there. It is important to note that they are active mediators between medical professionals, individuals diagnosed and their families. As such, there may be little need among people diagnosed for this new type of stakeholdership to develop, whereas researchers and other official institutions may prefer to engage in collaborations with patient representatives they are familiar with, which are already endowed with different types of knowledge and have vast resources to mobilize people.

The analysis of these bloggers' activities has also provided important insights regarding some of the conditions necessary to become online expert mediators. Thus, next to an official diagnosis, people's health needs to be stable enough for them to engage in various activities requiring a lot of time and energy. They also need to be able to communicate in ways which can capture and retain the interest of different stakeholders. Furthermore, those interested need either to financially afford giving up their jobs to dedicate themselves to the development of blogs or to be willing to accept sponsorship or another form of payment, thereby running the risk of losing their social benefits. More research is needed to understand the ways in which other kinds of knowledge and online skills shape the acquisition and articulation of interactional expertise, and into the differences and similarities concerning the mediation work undertaken by this new stakeholder category across different conditions. This chapter showed how individuals diagnosed with bipolar disorder responded to pronounced tendencies towards patient engagement by developing interactional expertise, and used the internet to become highly influential, thereby turning themselves into a new stakeholder category, what I called online expert mediators. The next chapter will describe a different response to such exhortations, which focuses on solidarity and the development of a new type of community.

Chapter 5

Digital biocommunities: solidarity and lay expertise about bipolar disorder

CHAPTER 5

5 DIGITAL BIOCOMMUNITIES: SOLIDARITY AND LAY EXPERTISE ABOUT BIPOLAR DISORDER

Expertise is shaped by the means through which it is acquired and enacted, by the goals it aims to achieve, and by the values that motivate and support such processes. In recent years, expertise about bipolar disorder has been shaped by the rise of personalized and precision medicine (Shin et al, 2016; Ozomaro et al, 2013; Evers, 2009), which many believe will lead to highly individualized approaches to health. Some commentators embrace the possibilities for diagnosis and treatment such visions of (mental) healthcare put forward, but others express concern that such approaches may lead to a loss of solidarity. Whereas autonomy has featured prominently in these debates, it is relatively recently that solidarity has started to garner more attention, and that scholars have begun to investigate how the pronounced focus on individualization at the heart of these visions might affect solidaristic practices. Important in this regard has been the perspective put forward by Prainsack and Buyx (2017), who have challenged the dominant belief that personalized and precision medicine would necessarily lead to radical forms of individualism, and argued that they could also prompt solidaristic approaches to healthcare. Such developments affect scientific and clinical practices surrounding bipolar disorder, as they prompt, for instance, psychopharmaceutic research to focus on increasingly more specific groups of patients, who not only share symptoms, but also certain genetic commonalities (McMahon & Insel, 2012). At the same time, these visions also influence the ways in which people diagnosed with this condition understand it and relate to others with the same diagnosis.

In this context, it is important to examine the relation between solidarity and lay expertise, a notion which is primarily collective, as it requires a community in order to be developed, enacted, and recognized. Despite worries that personalized and precision medicine will promote a type of healthcare where individuals focus only on their own needs and interests, in recent years online support groups have proliferated and diversified (Kaufman & Whitehead, 2016). At the same time, various health policies have been developed to facilitate the access of newly diagnosed people to such online platforms. It is therefore important to understand how solidarity and lay expertise relate to each other online. This is also necessary, because in the context of web-based mental health therapies, “informed supporters” (Barak et al, 2009), that is, people diagnosed with a certain mental health condition, play an active role in helping others with the same diagnosis by providing them with "more tailored feedback" (Barak et al, 2009:8). Yet, little is known about what motivates such solidaristic practices, nor how these supporters acquire the knowledge and authority needed to guide others.

In this chapter I therefore study the relationship between the online enactment of solidarity and the development of lay expertise about bipolar disorder. This relationship is particularly important, when expertise is understood as I have suggested, as a collective and practical achievement, realized through coordination and affective labor among stakeholders who occupy multiple and shifting positions within a complex ecosystem. By studying how solidaristic practices and lay expertise about bipolar disorder are related online, I put forward two separate arguments: (1) solidarity is enacted online (even) in a context dominated by the visions generated by personalized medicine; and (2) solidarity and lay expertise are closely related online. I show that the identification of important similarities prompts online contributors to engage in sharing practices, which allow them not only to enact lay expertise, but also to contribute to its collective development, as new knowledge is produced through the accumulation and synthesis of multiple insights.

I do so by focusing on the tension between appeals to solidarity and individualization in mental healthcare triggered by personalized and precision medicine and by considering how these tensions are taken up and reflected in the online exchanges of American and French contributors diagnosed with bipolar disorder. While liberal and individualistic approaches to (mental) healthcare have been dominant in the U.S., people diagnosed with mental health conditions have also joined self-help and support groups, as described in chapter 1, and have, thus, engaged in important ways in solidaristic practices. Such behaviors may become more prominent from now on, as solidarity has started to find its way also into the public discourse regarding the provision of (mental) healthcare, as evidenced by a growing number of publications on this topic (Cresswell & Spandler, 2016; McKeown, 2009). Nevertheless, the pronounced tendencies towards individual responsibilization which continue to characterize the (mental) healthcare landscape in the U.S. (Ter Meulen, 2015) make this confluence rather problematic. In contrast to the U.S., solidarity is framed as a national value in France, being strongly associated with the notion of fraternity, and having been a popular trope since the French Revolution. The popularity of this term is exemplified by its presence nowadays in the names of relevant and highly authoritative institutions, such as The Ministry of Solidarity and Health (*Le Ministère des Solidarités et de la Santé*).

In the analysis, I build upon the conceptualization of solidarity advocated by Prainsack and Buyx (2017) and on Gershon's (2010) notion of idioms of practice to put forward the concept of "digital biocommunities". I argue that people diagnosed with bipolar disorder develop digital biocommunities based on increasingly more specific commonalities, including shared idioms of practice regarding the use of digital technologies. I start by setting the theoretical scene with a brief discussion of the focus on individualization brought about by personalized and precision medicine and the threat to solidarity this is thought to represent. I then explain how these expectations may affect lay expertise and argue that affective labor needs to be taken into consideration when studying the relation between lay expertise and solidarity online. After providing an overview of the ways in which solidarity has been conceptualized, I show that the identification of numerous relevant commonalities prompts online contributors diagnosed with bipolar disorder to enact solidarity on blogs and fora by engaging in different types of sharing practices. Such exchanges lead to new knowledge, at both the individual and the collective levels, and therefore contribute to the development of lay expertise. A critical discussion of the potential impacts of the emergence of digital biocommunities is provided in the concluding discussion.

5.1 The individualization of healthcare: solidarity under threat

The rise of personalized and precision medicine has taken place in a context marked by the demise of national welfare systems and by the growing dominance of neoliberal tendencies, which have introduced a market logic in the provision of healthcare and have focused on individual empowerment as a means to achieve collective wellbeing. Personalized and precision medicine have been fueled by insights from genomics and related fields, and have profited from the availability and accessibility of a great number of online applications through which people can keep track of their health. These visions of healthcare target medical interventions that are tailored to the specific needs and circumstances of individual patients, who actively manage their health (Lupton, 2018; Prainsack, 2017). The collection and analysis of biological, environmental and lifestyle data are essential elements for the development of these approaches to healthcare and this is also one of the most important dimensions where the tension between individualization and solidarity becomes apparent. As increasingly more diverse types of data are required and found relevant, more responsibility is placed upon individuals. This often translates into encouragement for individuals to use digital technologies to (self)monitor various health processes and to behave in ways which would prolong their being in good-health and prevent or delay the development of health issues. Yet, in order to be able to make sense of an individual's various health markers, data from many other people are needed. Furthermore, insight into the state of health of any particular individual is achieved by bringing the health-relevant information obtained on/from that individual in relation with information acquired from larger groups.

Even though groups and sub-groups thus continue to play an important role in personalized and precision medicine, it is the possibility of providing personalized healthcare to individuals and the rights and obligations individuals have in this sense that have drawn the most attention among social scientists and patients, and have figured prominently in the public debate. By becoming more knowledgeable about the functioning of their bodies and their reactions to various chemical and environmental factors, individuals are thought to turn from passive recipients of care into collaborators of medical professionals, playing an important role in decisions about their treatment. Some commentators have thought that by enabling people diagnosed to engage in more substantial ways in processes of data collection, knowledge production and evaluation, such transformations may allow them to re-position themselves in relation to medical professionals, leading either to more equal or "democratic" relations, or to a reversal of the current state of affairs, as titles such as "Patient-Driven Health Care Models" (Swan, 2009) or *The Patient Will See You Now* (Topol, 2015) suggest. Individuals are also expected to be pro-active, and adjust their behaviors and habits, so as to prevent the development of health problems and to expand as long as possible their being in good health. Such expectations mean that people have to monitor their health at all times, not only when they do not feel well. In so doing, they have to pay attention to a growing number of aspects in their lives, given that health-related data have been expanded under precision medicine (Hedgecoe, 2004) to include a vast array of elements (Hogle, 2016; Weber et al, 2014).

The consideration of non-molecular elements in relation to health and illness has served to further highlight the differences existing between individuals, thereby threatening in certain understandings of personalized and precision medicine the possibility of establishing any meaningful types of (sub)groups. This tendency towards "radical" difference and its consequences are eloquently described by Prainsack and Buyx (2017:127):

> Because every patient is different, as this new version of personalized medicine assumes, their health and their diseases are different as well: individual differences in our genetic makeup, in our gene expression, in the microorganisms inhabiting our guts and bodies, in our lifestyles, diets and so forth render each of us, as well as our physiologies and pathologies, a unique expression of a particular state of health and disease in any given moment in time.

Nevertheless, even such instances of "radical" individualization require comparisons —with others as well as with oneself at different moments in time and under different circumstances— in order to determine the ways in which one differs from the rest, and what factors have influenced such a development. Thus, even in their most narrow or radical understanding, personalized and precision medicine require tremendous amounts of data from many people. This brings about a rather paradoxical state of affairs, where policy makers and researchers invoke solidarity in their appeals to individuals to provide health-related information, yet address the latter as autonomous and self-interested beings. A good illustration in this sense is the current name of the Precision Medicine initiative —All of Us — which conveys a vision of healthcare meant to bring collective benefits. Nevertheless, on its website, it is an individual reader that is encouraged to participate by being told that "the future of health begins with you" (June, 2018). For proponents of the Precision Medicine Initiative, individual autonomy appears to be needed to achieve solidarity. In France, however, the causal link seems to be reversed at times, as the French version of the name of The National Fund for Solidarity and Autonomy (*La Caisse Nationale de Solidarité Pour L'Autonomie*[15]) indicates. In this instance, solidarity is the means through which individual autonomy can be achieved.

There are important differences between proponents and detractors of personalized and precision medicine regarding their understanding of the impact of "radical" individualization upon solidarity. Supporters have welcomed the individualizing tendencies described above as leading to better and more efficient ways to provide healthcare, which they argued would ultimately be beneficial both for the individual *and* for society at large. Thus, by tailoring clinical investigations and therapeutic approaches to the specific needs and circumstances of every person (Wium-Andersen, 2017), people would be spared unnecessary tests or therapeutic approaches less likely to be successful. In their view, such approaches would enable the more effective attribution of funds in healthcare, thereby addressing and redressing a state of precarity triggered by a growing number of people diagnosed with (mental) health conditions and insufficient funds. Proponents of personalized and precision medicine have also argued that self-monitoring and the widespread adoption of mobile health, that is, of the use of mobile communication technologies for the provision of healthcare, enhance autonomy, as they enable people to gain more knowledge and control over their health (Steinhubl et al, 2013; Knoppers & Chadwick, 2005). Such practices have become very popular also in the field of mental health, where numerous online applications and technologies are being used to monitor people's state and to provide therapeutic interventions (Faurholt-Jepsen et al, 2018; Morris & Aguilera, 2012). Empowerment is understood in such instances to denote people's ability to make more informed decisions about their health, to plan ahead, to live longer on their own, even when diagnosed with serious conditions, and to interact with medical professionals from a more educated and knowledgeable position (Topol, 2015).

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[15] This institution was established in 2005, to distribute and oversee the national provision of financial help and assistance to people with disabilities and the elderly.

In contrast, detractors have argued that such a pronounced focus on individual responsibility threatens solidarity and may lead to new forms of inequality and discrimination (Prainsack & Buyx, 2012). For instance, seemingly preventable individual behaviors, such as smoking, the consumption of sugar and fats, a sedentary lifestyle, may lead to decisions whereby the people engaging in such practices may need to pay higher insurance rates, and/or may be denied access to certain forms of medical treatment and social provisions. According to critics, individual freedom and responsibility are often invoked in such instances to mask systemic forms of economic and social inequality, and may even help to perpetuate them. They also argue that proponents of personalized and precision medicine neglect the fact that by addressing individuals as unique from certain points of view, people may end up focusing more on what distinguishes them from others rather than on what binds them together. Dickenson's (2013) concern that personalized and precision medicine would bring about a shift from "We Medicine" to "Me Medicine" is illustrative in this sense.

Such concerns have prompted some scholars to challenge what they consider to be the "tyranny of autonomy" (Foster, 2009) in Western healthcare, and to think instead of ways in which solidarity could be furthered. Such commentators (Prainsack & Buyx, 2012; Baylis et al, 2008), have started by pointing out that the perspectives at the heart of personalized and precision medicine are based upon individuals seen as autonomous, rational beings, interested in maximizing their wellbeing. Arguing that understanding people as purely self-interested does not do justice to the important role of relationships, these scholars propose instead to approach individuals as relational beings, as people whose identities, values, needs, and perspectives are importantly shaped by the other people in their lives and by the socio-political context in which they live. Whereas the debate about the values that personalized and precision medicine promote remains to a large extent theoretical, a growing number of contributions have recently focused on how values invoked in support of innovative medical technologies and perspectives are manifested in practice (van de Werff, 2018; Swierstra, 2013). Particularly relevant here is Sharon's study (2017), which identified solidaristic practices at the heart of self-tracking, an endeavor generally thought to be highly individualistic and individualizing. There appears therefore to be an important contradiction between the individualizing tendencies many highlight in regard to personalized and precision medicine and the values people display in their health-related practices.

Since the development of lay expertise is predicated upon the existence of a community of people willing to come together and share information and experiences, the expectation of "radical" individualization in healthcare raises important questions about its future and the new shapes that it may take. It is unclear, for instance, how lay expertise, which is an inherently collective notion, could develop in a healthcare context where individuals are seen primarily as self-serving, nor is it any more apparent what relevance it may still have, when individual differences rather than commonalities are focused upon. Such questions are all the more important, since the hopes and fears generated by personalized and precision medicine have shaped the understanding of bipolar disorder and the search for treatment in ways which were more detailed in chapters 2 and 3. Given the emphasis on "radical" individualization in personalized and precision medicine, I have initially approached the data used in this chapter with the expectation of encountering numerous instances confirming the idea that individual needs, preferences, and approaches in mental healthcare have become dominant to the detriment of more collective challenges and concerns. Yet, on many blogs and fora people diagnosed with bipolar disorder continue to seek to understand their condition collectively. For instance, they try to make sense of the symptoms they experience by placing them in the broader context of their lives, by considering how their behaviors affect their families, friends and colleagues, and by comparing their experiences with those of others with the same diagnosis. This means that despite fears that "radical" individualization would prompt people to only care about themselves in relation to their health, solidarity remains an important value, that can be manifested and developed in online environments.

Chapter 3 has shown that the visions of personalized and precision medicine reach people diagnosed with bipolar disorder, but it has paid attention to the ways in which online contributors engage and seek to further the medical knowledge currently available on treatment effectiveness. This chapter focuses on the ways in which solidarity, a value that many consider to be under threat given the projected approaches to healthcare sketched above, is enacted online, and how it relates to the development of lay expertise. This is important because whereas a growing number of people seek health-related information online, limited knowledge is currently available on the types of interactions that encourage or limit the development of solidarity. Studying how online contributors diagnosed with bipolar disorder enact solidarity online and how such enactments affect the development of lay expertise contributes therefore to a better understanding of the ways in which values are made manifest on the internet, and how they relate to expertise in specific contexts.

5.2 Lay expertise and affective labor

In general, people diagnosed acquire lay expertise by becoming better informed about the medical knowledge available on their condition, by learning to interpret their own embodied experiences in light of this knowledge and by engaging in various tinkering practices to better manage their symptoms in their daily lives. While acquiring medical knowledge is an activity that in theory one may conduct individually, the other processes at the heart of lay expertise generally require multiple social interactions, as people diagnosed encounter others with the same condition and start making sense of their experiences by comparing symptoms, treatment reactions and life circumstances. Importantly, lay expertise is developed in conditions where people who are brought together by virtue of the same diagnosis develop feelings of trust, care and concern for each other. Previous studies on lay expertise have mainly focused on the epistemic processes through which people diagnosed become exceptionally knowledgeable about their condition, and have generally neglected the affective practices which support the processes of knowledge acquisition, exchange and development. More attention needs to be paid, however, to the affective labor people diagnosed engage in, because in sharing their illness experiences and medical knowledge with others, people often need to express or manage their own emotions and to be considerate of other people's feelings.

In studying the relation between solidarity and lay expertise, I therefore pay particular attention to the affective work online contributors engage in, as they come in contact with people experiencing different mood episodes or struggling with various medical and non-medical issues. I use the conceptualization of affective labor developed by Hardt and Negri, who define it as "labor that produces or manipulates affects such as feelings of ease, well-being, satisfaction, excitement, or passion" (Hardt & Negri, 2004:108), that take place at a pre-visceral stage of experience. Particularly relevant here is Hardt's (1999:89) view that affective labor is indicative of "processes whereby our laboring practices produce collective subjectivities, produce sociality, and ultimately produce society itself." This perspective allows me to focus on the personal and social value their online engagements may have for people diagnosed with bipolar disorder. Whereas a growing amount of value is nowadays generated from the cognition, communication, affect, and the immaterial actions of online "prosumers", the debate among scholars about the role of immaterial labor in digital media economics is still ongoing. Thus, Negri and Hardt (2004) join many others who have criticized users' engagement with digital technologies as a form of free labor (Lupton, 2014; Mitchell & Waldby, 2010; Waldby & Cooper, 2008; Terranova, 2000). More recently, however, a number of scholars (Andersson, 2017; Kneese, 2017; McCosker & Darcy, 2013) have shown that other forms of value or gratification that users of digital technologies may derive by engaging in immaterial labor need to be considered.

I join this latter group of researchers and in this chapter build particularly upon insights provided by McCosker and Darcy (2013), who argued that through their online activities, people diagnosed with a certain condition can create value that is *personal*, in that it allows them to engage in identity management while confronted with a serious condition; *network-enabling*, because it allows people to come together and share experiences with others in similar circumstances; and *social*, as such exchanges enable the management of a condition outside institutionalized forms of care. While the conceptualizations of lay expertise discussed in chapter 3 have focused on the acquisition and making manifest of different types of knowledge, this understanding of affective labor makes it possible to study lay expertise by approaching caring practices as an important, even though tacit, element thereof. The concept of affective labor is of further help because it showcases both the costs as well as the benefits online contributors diagnosed with bipolar derive from their interactions, and these are aspects which are at the heart of Prainsack and Buyx's (2017) conceptualization of solidarity, discussed in the next section.

5.3 The meaning of solidarity

While solidarity has been recently invoked in debates regarding health policy, there is great unclarity regarding its meaning. Solidarity is often defined as "the glue that keeps people together" (Komter, 2005:2), and the ambiguity of this concept stems in particular from the different ways in which the reasons for such social cohesion have been conceived. Thus, some scholars approach solidarity as a particular set of feelings and emotions (Mayhew, 1971), as moral (Etzioni, 1988) and "affective ties" (Parsons, 1952:157) which inform people's commitment to others. In such cases, solidarity is intertwined with the human capacity to experience and express sympathy, care, and concern for people in their immediate surroundings. It is thus thought to spring into being rather automatically, informed by common attachments (instead of rational considerations) among a relatively small number of people. Others understand solidarity as a characteristic of groups and societies (Durkheim, 1964; Weber, 1947), regulating the interactions between individual and community (Bayertz, 1998), and potentially furthering the common good. Van Oorschot and Komter noted in this sense that "[t]he main source of solidarity is a mutual sharing of each other's fate" (1998: 8). Thus, this perspective sees solidarity as largely the result of rational choices and calculations (Hechter, 1987), as based upon the acknowledgement of "shared identity" and "shared utility" (Van Oorschot & Komter, 1998), that is, on the recognition of common values, struggles, interests. Yet other scholars approach solidarity as a moral, universal, "inclusive" ideal (Dean, 1995), prescribing specific sets of orientations and behaviors which people should take up in order to increase social bonds in the heterogeneous societies we currently live in. Unlike the first approach, the last two allow for narrower as well as broader understandings of the group where solidarity develops, ranging from particular communities bound together by very specific worries and concerns, to nation states, or even to the whole of humanity.

Noting the abstract and different ways in which the concept of solidarity has been used, Prainsack and Buyx (2012; 2017) have put forward a practice-oriented definition of solidarity, which I used in the analysis presented in this chapter. According to Prainsack and Buyx (2012:346), "[s]olidarity signifies shared practices reflecting a collective commitment to carry 'costs' (financial, social, emotional, or otherwise) to assist others." (Prainsack & Buyx, 2012:346) Furthermore, while feelings and emotions may play an important role in its development, Prainsack and Buyx warn against reducing solidarity to them, and underline the need to approach it as "enacted commitments" (Prainsack & Buyx, 2017:42). This definition is particularly useful when studying the online interactions of people diagnosed with bipolar disorder, because of its focus on practices and of its broad understanding of costs, which enables me to consider the amount of time, effort, emotional availability, attention, and personal reflection that online contributors invest in their interactions with others as manifestations of solidarity. This approach is also helpful because of its broad view of what may constitute enactments of solidarity: "[a]n external manifestation of solidarity will typically comprise of an action by a person (or persons), but it could also take the form of a document, a policy or law, or another written or symbolic articulation of meaning" (Prainsack & Buyx, 2017:45). It thus makes it possible to consider the provision of online texts as informed by solidarity.

Prainsack and Buyx also view the emergence of solidarity as based upon people's recognition that they are similar to others in a respect that may be more or less substantive in nature. For instance, people diagnosed with bipolar disorder share important, durable commonalities with other people with the same diagnosis, which may move them to engage in solidaristic behavior. But they may also develop solidarity with others with whom they share more fleeting characteristics, such as, for instance, with other travelers upon hearing that their train has been cancelled and realizing that none of them will arrive at their destination and appointments on time. Similarity should therefore not be taken for granted, it is not given once and for all. This aspect is important for this analysis because it precludes me from approaching people diagnosed with bipolar disorder who are active online as a homogeneous group. It enables me to see the development of solidarity rather as an achievement and prompts me to pay attention to various contextual elements, to understand when and how they see themselves as similar or different to other people with the same diagnosis. At the same time, Prainsack and Buyx distinguish between charity and solidarity, arguing that for the practices that people display to be considered solidaristic, they need to have emerged among individuals or groups in symmetrical relations to each other, that is, among people who are the same in an aspect that is relevant in that particular context.

Another element that distinguishes Prainsack and Buyx's definition and approach to solidarity from other scholarly works on this topic is the relational understanding of personhood that underlines their conceptualization of solidarity. They see individuals' concerns, preferences, and values emerging in interaction with those surrounding them and shaped by the socio-cultural environment in which they find themselves. This means that they see people as simultaneously self-interested and concerned about the well-being of others. This perspective is also helpful in studying online interactions among people diagnosed with bipolar disorder, as it sensitizes me to the multiple meanings and goals such online exchanges may have and steers my focus onto the specific relational elements involved. As relations involve inclusions and exclusions, this approach prevents me from studying solidarity as something exclusively positive (Dean, 1995) and allows me to carefully consider who is left out as online contributors diagnosed with bipolar disorder enact lay expertise out of solidarity, and what role the online affordances of fora play in such developments.

5.4 Relevant similarities, solidarity and idioms of practice

In studying how solidarity relates to lay expertise on bipolar disorder online, I build upon studies which have shown that a common diagnosis (Epstein, 2007; Rabeharisoa & Callon 2002), and, more recently, similarities in one's genetic profile and potential health risks, facilitate the formation of collectives (Rabeharisoa et al, 2013). In this sense, Cambrosio and colleagues (2014:11) remarked that "[w]e presently witness a profound transformation of the configuration of biomedical practices, as characterized by an increasingly collective dimension". This analysis is particularly indebted to Rabinow's (1996) view that developments in genetics have led to the emergence of biosociality, that is, they have enabled the formation of new group and individual identities based on genetic and molecular insights. In this sense, Gibbon and Novas (2008:2) remarked that "[t]he creation of new opportunities for identifying with others who share a biological condition combined with the novel possibilities for acting upon disease has contributed to reshaping how patients organize themselves into groups and the kinds of activities they undertake."

Such insights are particularly relevant in a study on bipolar disorder, since in the aftermath of the Human Genome Project, the genetic causes of this condition have been intensely studied (Baart & Widdershoven, 2013; Craddock & Sklar, 2013; Barnett & Smoller, 2009), as has the role of genes in determining people's response to particular medications used in its treatment (Squassina & Pisanu, 2013). Thus, shared genetic and biological factors may serve as the relevant similarities based on which solidaristic practices may develop and this insight allows me to focus in the analysis on how individuals understand themselves and how they relate to others with the same diagnosis. This way, I can determine how "genomic solidarity" (Van Hoyweghen & Rebert, 2012) prompts people diagnosed with bipolar disorder to share their substantial knowledge about this condition with other online contributors and how it shapes the content of these exchanges. Importantly, this approach enables me to better distinguish whether and when the same diagnosis constitutes a sufficient common denominator or whether commonalities are sought at the level of everyday life or deeper, at the level of genes, molecules, and proteins, and may thereby transcend diagnostic borders. It can thus highlight how such different similarities shape how solidarity develops among people diagnosed with bipolar disorder.

While new types of knowledge transform the ways in which people understand their condition and relate to others, online their interactions are importantly shaped by the digital technologies they use, by the affordances of the social media where they seek and provide information. Thus "its [the internet's] interactivity and the interaction it allows for can facilitate the formation of specific points of view and new ways of articulating individual experience to collective positions." (Akrich et al, 2008:2) More recently, Sosnowy (2014:325) remarked that "the practice of utilizing digital and networked tools is accompanied by other social practices such as fostering community and mutual support, and negotiating medical relationships." Further emphasizing the impact of such technologies, van Dijck (2013) argued that by becoming deeply engrained in the daily lives of people, social media have transformed the very meaning and practice of sociality. Importantly, people figure out what aspects of a technology they use and how they use it in practice, by tinkering with it as they interact with others. Thus, not only do people use such technologies for social activities, but their very use is social, in that people "develop their beliefs about media and ways of using media within *idioms of practice*." (Gershon, 2010: loc 117) According to Gershon, "[i]dioms of practice point to how people have implicit and explicit intuitions about using different technologies that they have developed with their friends, family members, and coworkers" (ibid.) and "emerge out of collective discussions and shared practices" (ibid.)

Developed by Gershon in her anthropological forays into teenagers' use of technology, this concept is useful as it underlines the fact that a technology does not have the same meaning for all its users. Rather, people understand it differently depending on the context of their engagement with it, on the ways in which those around them use it, and on the prevailing social norms and values that prescribe: how it is used, what it can and should be used for, and what it is not and should not be used for. For instance, Gershon describes how the use of social media lead to the development of various idioms of practice regarding acceptable forms of break-up. While some people considered breaking up via an e-mail a more acceptable approach, because it was more personal and private, others found that it resembled too much a monologue, and preferred being notified about such an occurrence on social media, where turn-taking could unfold faster, and dynamic exchanges could easily occur. While in the early days of a technology, multiple idioms of practice can exist, in time certain practices may "solidify", as certain uses become widespread in specific contexts. The same holds true for early adopters of a technology, who need to integrate it and make sense of it in conjunction with the other technologies they use, whose use and meaning is thereby re-mediated or transformed.

In my analysis I combine the theoretical approach to solidarity developed by Prainsack and Buyx (2017) with the concept of idiom of practice (Gershon, 2010). This allows me to pay attention not only to how relations develop among people diagnosed with bipolar disorder by virtue of their common diagnosis and other relevant similarities, but also to consider how the choice of a particular online platform and the development of specific ways of using that platform's affordances contribute to how the people interacting on that platform relate to each other, thereby encouraging the emergence of solidarity or rendering it more difficult. More specifically, it enables me to identify new forms of sociality that may be developing among online contributors and to grasp how they are shaped by the affordances of fora. It further helps me to understand how people negotiate the topics that may be allowed under a specific forum thread, the type of exchanges that are permissible and encouraged, and the measures that are taken to develop a sense of community and to prevent less friendly or downright conflictual exchanges.

5.5 Methodology

Data have been collected based on the approach described in more detail in chapter 1. To avoid unnecessary repetition, in this section I only mention the aspects that are specific to this chapter. Data were collected from online interactive platforms, selected using the Google Index as a relevance indicator. Data come from one French forum, *Troubles Bipolaires*, and from one American forum, BpHope. *Troubles Bipolaires* is hosted on *Doctissimo*, and contributors are at liberty to initiate new threads and to manage them. Nevertheless, they need to comply with *Doctissimo*'s regulations and their online exchanges are overseen by the platform's moderators, who are medical professionals hired to ensure the quality of the medical information provided by the online contributors and the polite character of exchanges between them. They also have to alert the authorities when online contributors exhibit violent or suicidal tendencies that seem of an urgent nature. This is in contrast with the forum rules on *Bp Hope*, which state that it "is for only peer to peer (not moderator or professional) opinion and support." (bpHope, 2018)

Given the tremendous quantity of threads and comments which can be found on *Troubles Bipolaires*, I selected two threads which dealt with topics focusing on the lived experiences of people diagnosed and on the management of their condition. They were listed on the first two pages of thread titles on the forum, which means that they had been among the most recently contributed to at the time when the selection occurred. This, in turn, may be seen as another indicator of the relevance of these topics for online contributors diagnosed with bipolar disorder. One of the selected threads is entitled "À combien évaluez-vous votre humeur" [What value would you ascribe your mood], it was created on January 28, 2013 by an online contributor with the username *Nye293z*, and by February 20, 2018 it had gathered 17,102 comments. The other thread is called "Comment gérer la fluctuation de l'humeur" [How to manage mood fluctuation], it was initiated on July 24, 2014 by the online contributor with the username *carmentina*, and by February 20, 2018 it had received 1829 replies. The selected topics on *Troubles Bipolaires* were uncontroversial and invited people diagnosed with bipolar disorder to share their experiences and practices to heighten their collective knowledge. Fifteen threads from the *Bp Hope* Forum (see Appendix B, Table A.B.2), which had received at least 30 comments were selected. The decision to select forum threads with at least 30 comments was determined by the need for numerous interactions in order to study the development of community. As Table A.B.2 in Appendix B indicates, there is a considerable difference between the number of interactions studied on the French forum and the ones on the American forum. Even though the number of contributions on the two French threads was atypical even for *Doctissimo*, the decision to compare the interactions that unfolded there with the more limited ones on the American platform was informed by the desire to understand whether there was something specific about sociality on those two threads, whether the content, the contributors and/or particular uses of online affordances explained this difference. While chapter 3 focused on the treatment experiences of people diagnosed, for this chapter data were collected on two other important aspects in the lives of people diagnosed with bipolar disorder —the lived experiences of the symptoms of this condition, and personal and social life with/despite bipolar disorder. The analysis illustrates how the type of platform, the topic addressed, as well as cultural specificities shaped how solidarity influenced the enactment of lay expertise on the fora.

The data were analyzed using thematic analysis, which was described in more detail in the previous chapter, but I combined it with approaches derived from conversation analysis. This allowed me to understand how solidarity was enacted among people with different degrees of familiarity with each other, and to become aware of the different claims to lay expertise and of the ways in which online contributors switched between various positions in their dialogues. Given the emphasis upon "radical" individualization in personalized and precision medicine, I initially conducted exploratory line-by-line coding, to determine whether instances of solidarity enactment could be identified online. Since this was amply the case, a second round of coding was performed to identify patterns regarding the ways in which solidarity was enacted and its relation to lay expertise. Important themes emerged from repeated fine-tuning between the data collected and relevant theoretical concepts discussed earlier.

Conversation analysis is useful to analyze how elements of social life "are *locally accomplished* in and through talk and interaction" (emphasis in the original) (Rapley, in Seale, 2011:384), "how specific institutions (…) are *collaboratively produced* (Rapley, in Seale, 2011:388). While conversation analysis has historically been used to study spoken exchanges, I looked at the online interactions between online contributors on the forum as forms of naturally occurring exchanges. In so doing, I followed in the footsteps of other researchers who have started to study online interactions this way, arguing that they resemble offline dialogue in terms of turn-taking, action and reaction (Kaufman & Whitehead, 2016; Armstrong et al, 2012). Thus, conversation analysis was particularly helpful to study the effectiveness of the support provided by others as experienced by the person "appealing" (Dean, 1995) to it, through a close examination of how successful as well as unsuccessful interactions unfolded. In combination with thematic analysis, conversation analysis also allowed me to better understand how online contributors displayed the development of a "shared idiom of practice" through the specific use of different online affordances and of visual elements, such as images and emoticons.

5.6 The relation between solidarity and lay expertise about bipolar disorder online

5.6.1 Relevant similarities

On the platforms I studied, online contributors were initially brought together by one important similarity: they had all been diagnosed with bipolar disorder. Behind this rather obvious commonality, many other similarities were conflated, such as a similar orientation towards bipolar disorder and similar approaches in trying to make sense of it and to address it effectively. For instance, on the fora discussed here, long-lasting interactions developed among people who understood bipolar disorder as a biological condition, determined by genetic and neurological factors. Such a perspective was apparent, for instance, when a few online contributors joked on the thread "Comment gérer la fluctuation de l'humeur" [How to manage mood fluctuation] about not having children, in order to prevent the transmission of their "bipolar genes". Others referred to the activity of neurons and to faulty circuits in their brain to explain some of their behaviors. This not only means that these online contributors embraced a medical perspective on the causes of bipolar disorder, but they also shared the conviction that this condition could be managed through medication, and that scientific progress would one day make its successful treatment possible, as many of their posts and comments indicated. The online contributors studied also valued knowledge and personal agency, and they tried to educate themselves about bipolar disorder to better manage their condition. Furthermore, to the extent that it was possible, they all tried to live fruitful lives, dedicating themselves to their jobs and families, or pursuing activities they were passionate about, such as horse-riding, drawing, learning foreign languages.

Another commonality online contributors shared was the difficulty, despite such general orientations and practices, to narrow down the meaning and influence of bipolar disorder. For instance, while in terrible pain because of trigeminal neuralgia, a chronic pain condition that affects the trigeminal nerve, *carmentina,* the initiator of one of the threads studied, confessed to feeling uncertain regarding the source of her pain. Since none of the procedures undertaken had been very successful, she had started doubting whether the pain she was experiencing was solely caused by the trigeminal nerve or whether her diagnosis of bipolar disorder also played a role, either by rendering her more sensitive to the experience of pain or more resistant to the effects of the medications prescribed. Similarly, *paige14*, a contributor on the forum *bpHope*, confessed to being uncertain about the degree to which the loss of memory she was experiencing was a side-effect of ageing, of hormonal changes induced by the menopause, or was informed by bipolar disorder. She believed this condition may have contributed to accelerating the memory loss either through the neurological changes it had produced in her brain or as a result of the long-term side-effects of the medications she had taken for its management. Such common uncertainties often implied that the contributors engaging in conversation about these topics resembled each other in other aspects of identity as well, such as age, gender, and level of education.

Online contributors also identified additional similarities in the forms that certain symptoms took for them. For instance, many contributors on *Doctissimo* stated that changing their location or traveling posed difficulties for them, as the exchange below illustrates:

jechoisislavie
Profil : Doctinaute d'or

1. Posté le 19/07/2015 à 20:49:17
2.
3.

1. ⚠

cathy290 a écrit :

Que je parte loin ou pas c'est pareil une fois que j'ai mes repères ça va, il faut que je m'adapte au lieu.
Parfois ça se fait tard....

Afficher plus

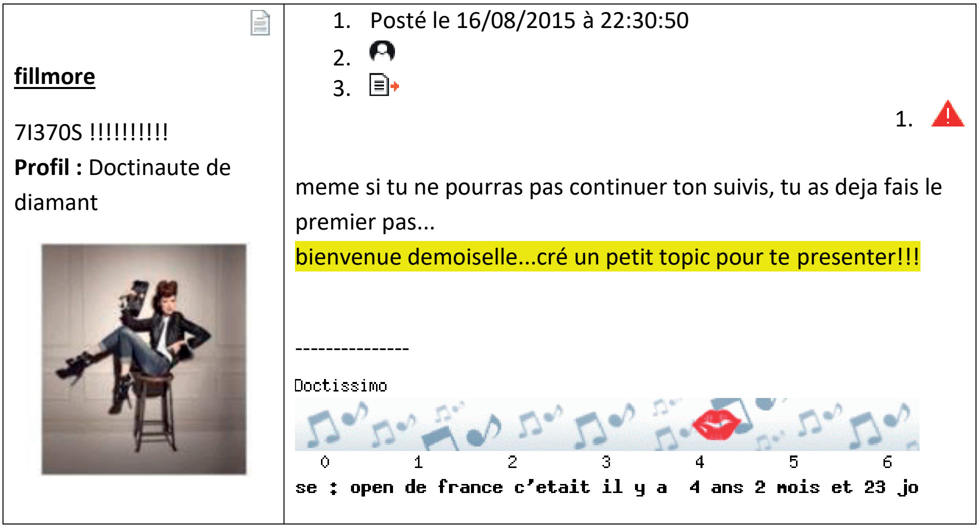
Idem, mais c'est pour ça que je pars souvent dans des lieux connus. L'adaptation peut être longue pour moi... Décidément les bipos ont vraiment tendance à fonctionner pareil...

1. 0

USERNAME	FORUM CONTRIBUTION
Jechoisislavie	**cathy290 wrote:** Whether I go far away or not, it’s the same. Once I have my bearings, it's ok, I need to get used to the place. Sometimes this only happens late ... Show more…
	Same here, but that's why I often go to places I know. The adaptation can take long for me ... Decidedly the bipos [people diagnosed with bipolar disorder] really tend to function the same way ...

This exchange reveals that for both contributors adapting to a new location is difficult and takes time. That identifying common similarities contributes to people feeling part of a community is emphasized in the last part of the contribution of *jechoisislavie*, where the multiple contributors who had hitherto confessed to the same difficulties function implicitly as mediators between the individual position —for me— and that of all people diagnosed with bipolar disorder. The last sentence also highlights the important epistemic character of such exchanges, as it shows that *jechoisislavie* uses the insights shared by other online contributors to make inferences about all people diagnosed with this condition and their functioning.

Specific engagements with the online affordances of the forum or the development of a shared idiom of practice assisted online contributors on *Doctissimo* to more easily identify commonalities. For instance, contributors on the thread "Comment gérer la fluctuation de l'humeur" [How to Manage Mood Fluctuation] developed the habit of instructing new comers to provide an elaborate personal description on a separate location on the forum, as the following excerpt illustrates:



fillmore

7I370S !!!!!!!!!

Profil : Doctinaute de diamant

1. Posté le 16/08/2015 à 22:30:50
2.
3.

1.

meme si tu ne pourras pas continuer ton suivis, tu as deja fais le premier pas...

bienvenue demoiselle...cré un petit topic pour te presenter!!!

Doctissimo

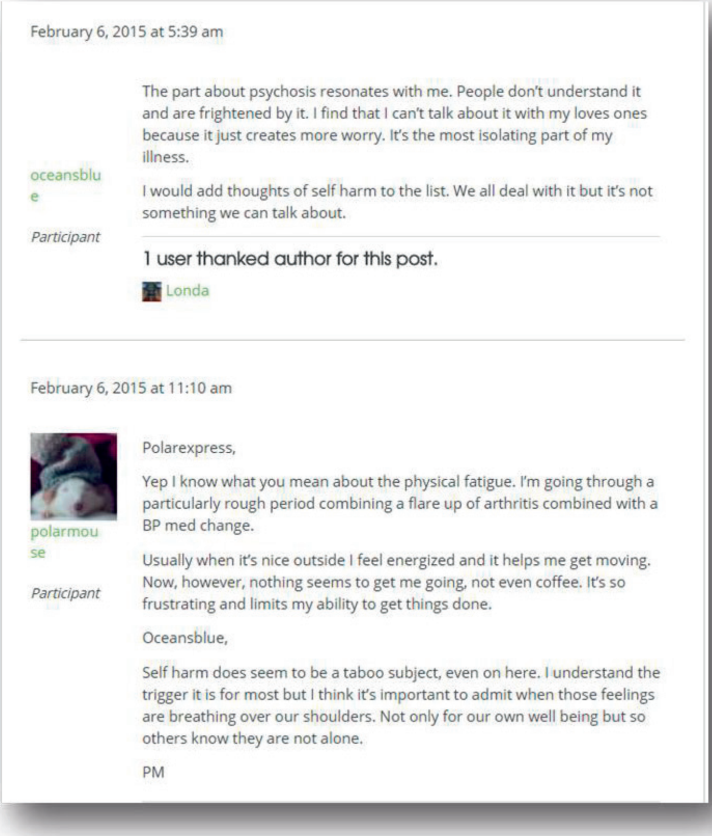
se : open de france c'etait il y a 4 ans 2 mois et 23 jo

USERNAME	FORUM CONTRIBUTION
fillmore	even if you won't be able to continue with your follow-up, you have already taken the first step ... welcome young lady ... create a short topic to introduce yourself !!!

Newcomers were advised to introduce themselves more elaborately if and when they felt comfortable enough to do so, once they had become more familiar with the other people on the thread. This helped online contributors discover that they had lived in the same town, that they had similar family circumstances, or were fond of the same type of pets. Yet, the provision of a personal description sometimes rendered one's newcomer status more obvious, as not everyone was aware of the differential use of various spaces on the forum. For instance, *Floraelle* (August 16, 2015), to whom *fillmore* reacts in the excerpt above, typed a very detailed personal introduction as a comment on the same thread rather than as a distinct thread, as was customary among contributors to *Doctissimo*. The latter approach is part of an idiom of practice developed among the users of this specific platform. On the other online platform studied, the discovery of additional commonalities was assisted through the development of threads with a playful, socially informative character, such as "where were you when…" (*bpHope*) or "Sharing quotations" (*bpHope*). Next to the structured provision of such personal information, online contributors could identify similarities with other people diagnosed with bipolar disorder based on their profile photos and online signatures. As the image in the excerpt above indicates, such online affordances allowed online contributors to highlight their interests or hobbies, such as music, dancing, playing tennis, etc.

5.6.2 Enacting solidarity

Having identified such similarities, online contributors displayed solidarity by sharing personal strategies to better manage bipolar disorder in daily life, by informing others about the results of their self-experiments, and by creating a safe environment for online contributors to express their concerns, preferences, and challenges. The following exchange illustrates how the acknowledgement of important similarities led to the development of solidarity, thereby moving people to share their insights online:



February 6, 2015 at 5:39 am

oceansblue

Participant

The part about psychosis resonates with me. People don't understand it and are frightened by it. I find that I can't talk about it with my loves ones because it just creates more worry. It's the most isolating part of my illness.

I would add thoughts of self harm to the list. We all deal with it but it's not something we can talk about.

1 user thanked author for this post.

Londa

February 6, 2015 at 11:10 am

polarmouse

Participant

Polarexpress,

Yep I know what you mean about the physical fatigue. I'm going through a particularly rough period combining a flare up of arthritis combined with a BP med change.

Usually when it's nice outside I feel energized and it helps me get moving. Now, however, nothing seems to get me going, not even coffee. It's so frustrating and limits my ability to get things done.

Oceansblue,

Self harm does seem to be a taboo subject, even on here. I understand the trigger it is for most but I think it's important to admit when those feelings are breathing over our shoulders. Not only for our own well being but so others know they are not alone.

PM

oceansblue's comment shows that he feels comfortable enough to accept the thread initiator's invitation to contribute to a list of less-talked about symptoms experienced by people diagnosed with bipolar disorder. The first paragraph is important because it highlights the relational way in which this contributor experiences his condition, as well as the affective labor he performs, as he takes into account the impact certain topics may have on his family and acts accordingly. The contrast between such avoidance behaviors towards one's family and the openness of one's online contributions highlights the important social function fulfilled by online platforms. This might also explain his willingness to run the risk of being criticized by many online contributors for putting forward a symptom such as self-harm, which even though not uncommon, remains, nonetheless, to a certain extent taboo even among many people diagnosed with bipolar disorder. From this point of view, *oceansblue* may not only be sharing an important insight, but he may also be testing the waters for other contributors who may feel the need to talk about their experiences in this regard but may not have the courage to initiate such a conversation. The switch from "I" to "we" in the second paragraph indicates that *oceansblue* feels solidarity with the other online contributors based on a common symptom.

The reply *oceansblue* receives from *polarmouse* confirms the solidaristic ethos underlying such sharing practices, as she encourages him to continue to talk about self-harm as a form of support to others, as can be seen in the last sentence. While she does not dwell upon it, *polarmouse* acknowledges that such sharing practices also further the well-being of the contributor. This is important because it ties in with the idea put forward by Praisanck and Buyx (2017) that when engaging in solidaristic behavior, people act simultaneously out of self-interest and concern for others. Interesting in this excerpt is also the appreciation that *oceansblue*'s post received from *Londa*. While this is a light form of participation, it shows that online affordances on this forum importantly contribute to the development of relationships and ensure a minimal degree of reciprocity among information providers and information seekers.

In other instances, online contributors enact solidarity by putting time and effort into identifying reliable sources of information for those with whom they frequently interact. As *carmentina* was about to undergo a surgical procedure that she was worried about, other contributors on the forum engaged in various types of work to assist her:

carmentina
la Vie
Profil : * Doctinaute d'Honneur *

1. Posté le 12/03/2015 à 05:08:02
2.
3.

1. ⚠

mais, tu me fais penser que je devrrrais rechercher un forum bien spécifique pour les "gens dans mon cas".

si l'un d'entre vous veut bien faire une recherche pour moi, je suis preneuse.

1. 0

---

fillmore
7I370S !!!!!!!!!!
Profil : Doctinaute de diamant

1. Posté le 12/03/2015 à 15:32:11
2.
3.

1. ⚠

alors...
sur docti

ensuite
une discussion sur vulgaris

apres
un forum

et puis
un temoignage positif

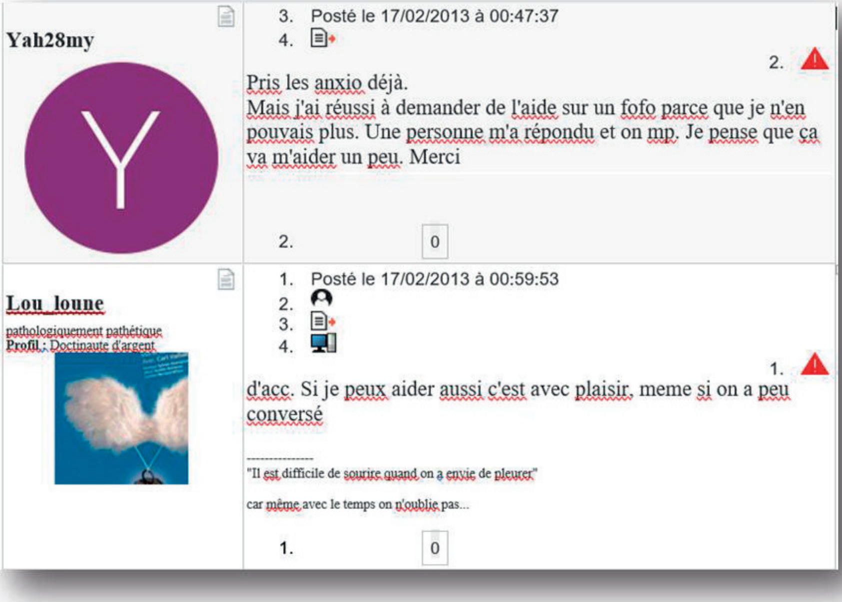
bon apres faut fouiller...
la je doit me sauver chercher mon fils....
mais voila deja un peu de lecture non medicale!!

se : open de france c'etait il y a 4 ans 2 mois et 23 jo

USERNAME	FORUM CONTRIBUTION
carmentina	but you make me think that I should look for a very specific forum for "people in my case". if one of you is willing to do a search for me, I'm interested.
Fillmore	so.... on docti next a discussion on vulgaris then a forum and afterwards a positive testimony That done, you still need to look around… Right now I got to go pick up my son… But you already have a bit of reading that is not medicine-related!!

The first part of *carmentina*'s reply highlights the tendency among online contributors to seek interactions with others with whom they share relevant similarities, and indicates that individuals may be simultaneously members of multiple online communities, where they focus on different issues of interest. *fillmore*'s reply shows that she invests time in the context of a busy schedule and uses her online experience and personal knowledge of *carmentina* to identify online sources of information that she believes would be of help to her online friend. The small description *fillmore* provides about the online platforms she selected indicates that for these online contributors, fora and other interactive online platforms, where people can engage in dialogue, are important sources of lay expertise, which they find useful in case of doubt or anxiety. The list also reveals the affective labor performed by *fillmore*, as she makes sure to also include a positive testimony, to further reassure *carmentina*.

Solidarity is also enacted as people offer to support others, when they experience a serious episode, as the following exchange illustrates:



Yah28my

3. Posté le 17/02/2013 à 00:47:37
4.

2.

Pris les anxio déjà.
Mais j'ai réussi à demander de l'aide sur un fofo parce que je n'en pouvais plus. Une personne m'a répondu et on mp. Je pense que ça va m'aider un peu. Merci

2. 0

Lou_loune

pathologiquement pathétique
Profil : Doctinaute d'argent

1. Posté le 17/02/2013 à 00:59:53
2.
3.
4.

1.

d'acc. Si je peux aider aussi c'est avec plaisir, meme si on a peu conversé

"Il est difficile de sourire quand on a envie de pleurer"

car même avec le temps on n'oublie pas...

1. 0

USERNAME	FORUM CONTRIBUTION
Yah28my	I had already taken the anxiolytics… But I've managed to ask someone to help me on a forum because I couldn't take it anymore. Someone reacted and we're talking via private messages. I think this will help me a bit. Thanks.
Lou_loune	O.K. If I can also be of any help, it would be my pleasure, even if we haven't talked much…

The importance of the help online contributors provide each other is highlighted here, as *Yah28my* frames the interaction with another person diagnosed with bipolar disorder via private messaging on a forum as an additional therapeutic means to manage anxiety. *Lou-loune*'s reply illustrates the willingness of online contributors to help others with whom they share a relevant similarity even when they do not know each other well. While *Lou-loune* describes herself as "pathologically pathetic", as she mentions underneath her username, her reaction suggests that engaging in solidaristic practices online may constitute a way for her to claim a different identity, of someone strong and capable enough to support someone else in a dark moment.

Sharing one's experiences and insights is an important way in which online contributors enact solidarity, highlighted by the fact that many other contributors ascribe therapeutic effects to such information, as the following excerpt indicates:

> I would highly recommend reading some of these blogs if you're feeling anxious about your memory. Anxiety will probably make the memory stuff worse. It does for me, which why I bookmarked the blog topic so I could read blogs over again and feel less frightened. (*paige14*, March 30, 2017)

paige14 highlights here the therapeutic effects of blogs on topics of concern, as well as the role online affordances play in facilitating these effects, as the bookmarking function allows her to access the desired information despite memory loss at any moment when she needs it. This fragment also highlights the emotional and affective impact blogs can have, presumably not only because of the tips and strategies shared by people struggling with similar issues, but also due to the awareness that one is not the only one facing such challenges. From this point of view, these fora resemble the traditional self-help groups described in chapter 1. Since *paige14*'s comment was made on a thread where people were considering the impact of aging on bipolar disorder, the insights provided by other people in similar circumstances may also help "naturalize" certain experiences, framing them as part of a degenerative process all people (diagnosed with bipolar disorder) undergo rather than as an individual occurrence, as the faulty response of the organism or brain of one specific individual. From this point of view, online interactions may provide people diagnosed with bipolar disorder with a welcome respite from the questions of guilt and individual responsibility that individualizing discourses propagate.

5.6.3 The "costs" of solidarity and online lay expertise

As the examples above have shown, people diagnosed with bipolar disorder enact solidarity by providing information, advice and support through well-balanced and carefully considered comments. For instance, some contributors acknowledge that they have read the reactions of others who were sharing their experiences and asking for input, but they want to take some time to reflect before providing them with an answer. In other cases, providing others with information about the effects and side-effects of medications they have taken at some point along their bipolar trajectories involves rather painful journeys into their past, a revival of periods marked by pain and suffering. Furthermore, people diagnosed with bipolar disorder share with others with whom they acknowledge certain similarities strategies to better manage their condition at the level of daily life, which are often the result of personal effort and extensive tinkering.

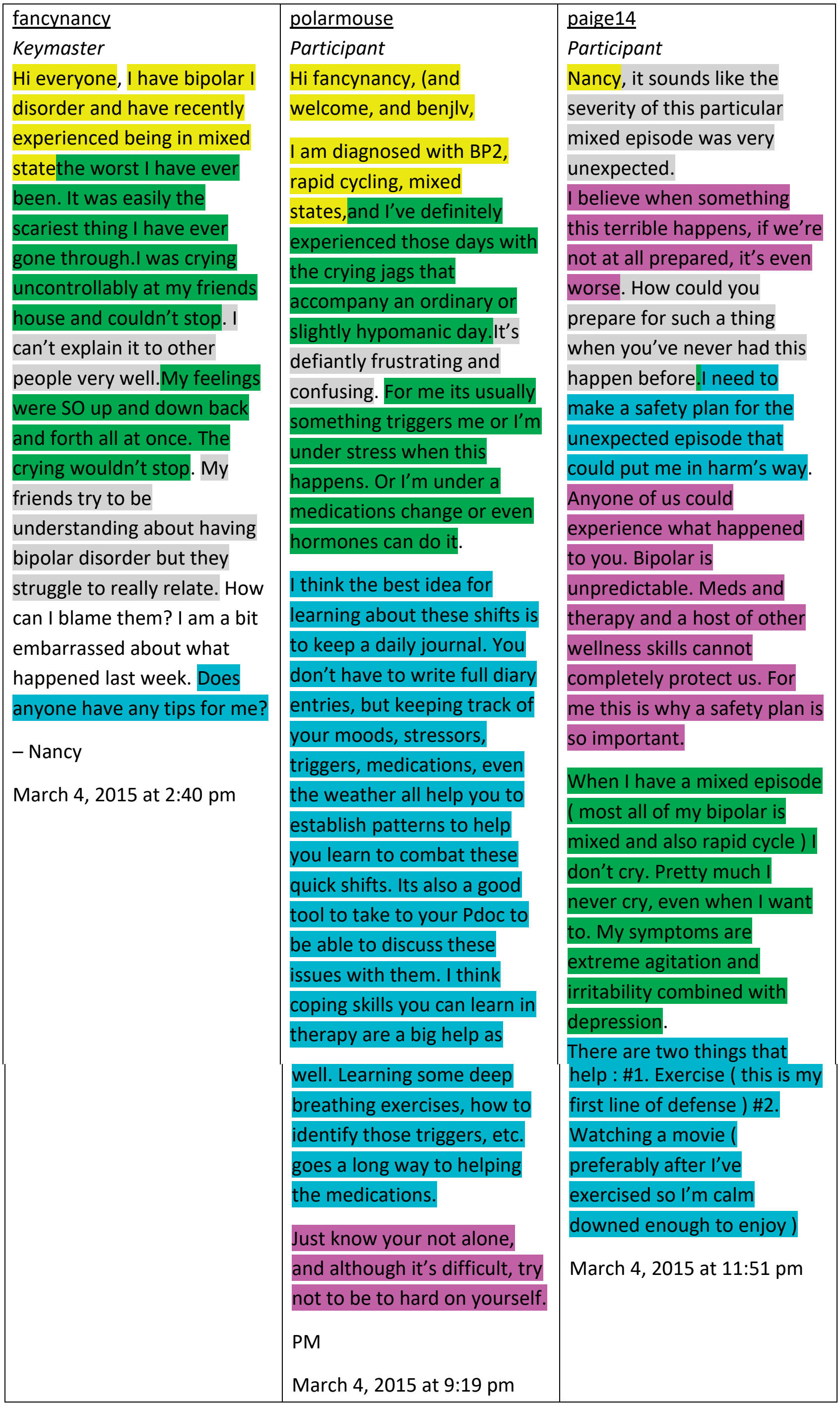
To the extent that the detailed descriptions some online contributors provide of their behaviors during depressed or manic states involve elements which place them in a rather negative light, such posts may be seen as informed by solidarity, as their authors seek to help others by furthering their knowledge about bipolar disorder while also benefitting themselves from a more careful consideration and reflection upon their behaviors.

Another important manifestation of solidarity is the online contributors' emotional availability in their interactions with others with the same diagnosis, as they listen to them with respect and empathy. Furthermore, they engage in affective labor by considering the effects their reactions might have upon them, or by paying attention to the personal preferences of the person they address in order to personalize their advice and to render it more appealing. At the same time, they seek to inspire people who are depressed or going through a difficult time to persevere in their efforts, they provide support and create an online space where other online contributors feel safe enough to share their concerns, views, and experiences.

5.6.4 From solidarity to lay expertise

In the previous sections of this analysis, I have shown that people diagnosed with bipolar disorder enact solidarity online by providing detailed descriptions of their personal experiences of this condition, by sharing medical advice and personal strategies, and by providing emotional support to others when experiencing a mood episode. I have also described how such solidaristic practices are based upon the identification of important similarities and involve different types of costs online contributors are willing to undergo to benefit themselves *and* others. In what follows, I show that such sharing practices enable individual online contributors to enact lay expertise, but they also contribute to the collective development of lay expertise, as new knowledge is distilled from the multiple experiences and insights that are brought together on these threads. The reactions provided in Table 5.1 below are a good example of this. The contributions are provided sequentially from left to right. While on the forum, *fancynancy*'s post was followed by one from *benjlv*, to whom *polarmouse* refers, I did not provide that contribution, because it did not directly engage with *fancynancy*' request for help, unlike the reactions provided here. In order to show how *fancynancy* ordered different elements in her statement and to indicate how those who reacted to her statement responded to these specific elements, I used different colors to distinguish between them. Thus, yellow marks introductory information the contributors provide about themselves, green highlights the symptoms described; blue denotes the request and provision of support; magenta denotes elements with a solidaristic character, whereas grey denotes the expectation and expression of empathy and understanding

Table 5.1 Excerpt from an online interaction on the experience of mixed states



fancynancy	polarmouse	paige14
Keymaster	*Participant*	*Participant*
Hi everyone, I have bipolar I disorder and have recently experienced being in mixed statethe worst I have ever been. It was easily the scariest thing I have ever gone through.I was crying uncontrollably at my friends house and couldn't stop. I can't explain it to other people very well.My feelings were SO up and down back and forth all at once. The crying wouldn't stop. My friends try to be understanding about having bipolar disorder but they struggle to really relate. How can I blame them? I am a bit embarrassed about what happened last week. Does anyone have any tips for me? – Nancy March 4, 2015 at 2:40 pm	Hi fancynancy, (and welcome, and benjlv, I am diagnosed with BP2, rapid cycling, mixed states,and I've definitely experienced those days with the crying jags that accompany an ordinary or slightly hypomanic day.It's defiantly frustrating and confusing. For me its usually something triggers me or I'm under stress when this happens. Or I'm under a medications change or even hormones can do it. I think the best idea for learning about these shifts is to keep a daily journal. You don't have to write full diary entries, but keeping track of your moods, stressors, triggers, medications, even the weather all help you to establish patterns to help you learn to combat these quick shifts. Its also a good tool to take to your Pdoc to be able to discuss these issues with them. I think coping skills you can learn in therapy are a big help as well. Learning some deep breathing exercises, how to identify those triggers, etc. goes a long way to helping the medications. Just know your not alone, and although it's difficult, try not to be to hard on yourself. PM March 4, 2015 at 9:19 pm	Nancy, it sounds like the severity of this particular mixed episode was very unexpected. I believe when something this terrible happens, if we're not at all prepared, it's even worse. How could you prepare for such a thing when you've never had this happen before.I need to make a safety plan for the unexpected episode that could put me in harm's way. Anyone of us could experience what happened to you. Bipolar is unpredictable. Meds and therapy and a host of other wellness skills cannot completely protect us. For me this is why a safety plan is so important. When I have a mixed episode (most all of my bipolar is mixed and also rapid cycle) I don't cry. Pretty much I never cry, even when I want to. My symptoms are extreme agitation and irritability combined with depression. There are two things that help : #1. Exercise (this is my first line of defense) #2. Watching a movie (preferably after I've exercised so I'm calm downed enough to enjoy) March 4, 2015 at 11:51 pm

While this exchange did not unfold in real time to allow for proper conversational analysis, its guiding principles were applied here, as particular attention was paid to the ways in which different elements were organized in each individual reaction, and on the effects achieved by their specific ordering. The analysis was further guided here by insights provided by Wynn and Bergvik (2010) in a study on the interactions between psychotherapists and their patients in regard to the expression of empathy. While the focus here was not on empathy, but on the ways in which the request and provision of support contributed to the enactment of lay expertise, the sequences below follow a two-part sequence Wynn and Bergvik (2010) described. Thus, a first "troubles-talk" (Jefferson, 1988) sequence, where a participant (*fancynancy*) describes feelings, thoughts, and states, which indicate the difficult situation she finds herself in, is followed by a second sequence, where another participant (*polarmouse*) provides a supportive response. While Wynn and Bergvik (2010) noted the presence of a third sequence, where the initial contributor reacted to the second participant's contribution, here another participant provides another second sequence, in that p*aige14* reacts directly to *fancynancy*'s post, without any direct mention to *polarmouse*'s reaction. Table 5.1 shows that these different contributors combined in different ways common elements, which allowed them to assume different positions, but it also indicates that there were significant similarities between the forum participants, which moved them to share effective coping strategies.

The sequence opens with *fancynancy* greeting everyone and introducing herself by specifying the type of bipolar disorder she was diagnosed with, followed by a description of her experiences of the mixed state. While thus far her reaction was similar to many others provided on the thread, a significant feature of this post is the question at the end, which serves as a direct request for advice and support based on the same diagnosis and similar experiences. This also indicates that *fancynancy* positions herself as a non-expert in regard to the management of this group of symptoms, but believes other forum contributors to be more knowledgeable. By reacting to her post and thereby responding to her interpellation, *polarmouse* and *paige14* position themselves as experts in this context, and their posts include various elements meant to justify it. Interesting about the way in which *fancynancy* organizes her post is the new theme she introduces in the middle of her description of the symptoms she experienced, which is highlighted in grey in Table 5.1. Through it, this contributor both acknowledges her communicational difficulties, but also seems to suggest that people who lack experiential knowledge of the symptoms she describes may have a hard time properly understanding them. This is further reinforced by the question at the end, which suggests that she expected people on the forum to be able to provide her with advice other people in her immediate surroundings were not able to give her.

polarmouse seeks to convey alignment with the experiences recounted by *fancynancy* by mirroring to a large extent in her reply the organization the latter opted for in her post. Like *fancynancy*, she also begins her sequence with a greeting, followed by information about her diagnosis, and a description of her experiences with mixed states. This serves both to legitimate her knowledge, showing through the description she provides that she knows what they entail, and also to highlight this as an important element she and *fancynancy* have in common. *polarmouse* responds reassuringly to the latter's expectation of empathy, but moves on to indicate that she is more knowledgeable, by showing her awareness of particular triggers and by using medical terms, such as "hypomanic". The next and more extensive part of her reply is the response to *fancynancy*'s direct question, and consists of various suggestions on how the latter could better manage her mixed states. It is noteworthy that this contributor expands the relational horizon sketched by *fancynancy* in order to include medical professionals, suggesting that she could discuss her diary entries with them and learn breathing exercises from them. The last sentence in the advice section of *polarmouse*'s reply also illustrates the complex perspective she has on what would constitute an effective therapeutic approach for *fancynancy*, and conveys her belief in the necessity of an active engagement of the person diagnosed. *polarmouse* concludes her post with a display of solidarity, as she encourages *fancynancy* to think of herself as part of a community and provides a caring suggestion in reaction to the latter's statement that she was "a bit embarrassed" by her behavior. The similarity she presumes to exist between her and *fancynancy* is highlighted in this part by the preemptive statement "although it's difficult", which shows that she is aware both of how the contributor might react to this suggestion and of the actual effort required to follow up on it.

paige14 organizes her reply to *fancynancy* in a different way, dedicating a large part of her contribution to the expression of empathy and the display of solidarity. The first sentence is meant to authenticate f*ancynancy*'s experiences as well as to soothe the feelings of embarrassment the latter described. The switch from "I" to "we" in the following sentence is important in relation to solidarity, as it shows that *paige14* thinks of herself, *fancynancy*, and presumably other people experiencing the same symptoms as part of a community, herewith echoing the last part of *polarmouse*'s post. At the same time, *paige14* distinguishes among people diagnosed with bipolar disorder based on their familiarity with the condition, as she pleads to *fancynancy* not to feel guilty, by framing her as a novice who could not have known any better. *paige14* nuances this perspective by making an important distinction in the level of agency she ascribes people diagnosed with bipolar disorder and to the condition itself. Thus, she describes bipolar disorder as "unpredictable" and capable to catch off guard any person diagnosed, which serves to support her suggestion of creating a safety plan.

This perspective is in contrast to the one advocated by *polarmouse*, who provided a more optimistic outlook, where bipolar disorder could be effectively managed through various strategies. In *polarmouse*'s reaction, this was indicated in the blue-colored section through the enumeration, which served to highlight the various options at one's disposal. One's considerable degree of agency was further emphasized through the use of the superlative adjective "best" and of qualifying adjectives with a positive (contextual) value, such as "big help", "good tool", "long way" in relation to her suggestions. Without directly interpellating *polarmouse*, *paige14* engages with each of the elements the former mentioned in her suggestions on how to manage mixed states, thereby resisting the largely optimistic tone of the latter's message. This indicates a possible lack of alignment with *polarmouse*'s experiences regarding the effectiveness of the approaches she suggests. This move is in contrast with the solidaristic ethos of her overall message, where she refers to people diagnosed as "us". At the same time, it is possible that *paige14* conceives of individualization in ways which allow one to have distinct individual experiences, while still being part of a large community of sufferers, as can be noted in the positioning of "us" and "for me" next to each other at the end of the magenta underlined sequence. This is further reinforced in the next paragraph, where *paige14* states that she experiences mixed states in opposite ways to those described by *fancynancy* and *polarmouse*, yet this does not prevent her from sharing her own coping strategies. It would therefore appear that this contributor bases her solidaristic practices on the same diagnosis, irrespective of differences in the actual manifestations of the condition. Furthermore, she seems to consider the same diagnosis as a sufficient commonality for the same strategies to be effective, judging from the last part of her post. This is where *paige14* reacts to *fancynancy*'s request for advice by sharing two personal strategies, and these elements mirror through their position the location of *fancynancy*'s question in her post, thereby providing a sense of completion.

While in certain instances online contributors enact solidarity by sharing their insights on bipolar disorder and thus lay expertise on this condition develops as an effect of such solidaristic practices, there are also online exchanges that indicate that solidarity and lay expertise are co-enacted. The excerpt below is illustrative in this sense:

> C'est vrai que tu es courageuse c'est incroyable j'ai eu les larmes aux yeux.
> J'aimerai tellement pouvoir t'aider je ne sais quoi te dire je te jure suis triste pour toi Tina
> J'ai toujours dit que je voudrai que personne ne connaisse les douleurs que j'ai et voilà que ça t'arrive à toi et ça me rend triste et je te sens souffrir et je sais pas quoi faire.

> Sache que les bruits violents, la fatigue, la peur, la tristesse, la colère, l'énervement, la panique vont accentuer tes douleurs. Le froid aussi les choses brûlantes par contre ce qui est doux va te soulager
>
> Ne prend pas trop d'antalgiques Parce que plus tu te sentiras endormi plus Ca va tirer niveau musculaire le cerveau prend ça comme un signal c'est à dire attention moi je ne lâche rien. Est ce qu'on t'a proposé de la cortisone à faible dose ? Sur mon visage ça marche bien mais sur mes jambes ça n'a jamais rien donné.
>
> Bonne et douce nuit.
>
> [It is true that you are courageous it's amazing I had tears in my eyes [when reading your account].
>
> I would love to be able to help you but I don't know what to say to you I swear I'm sad for you Tina
>
> I have always said that I didn't want anybody else to know the pains I'm experiencing and now it happens to you and it makes me sad and I feel your pain and I don't know what to do.
>
> Know that violent noises, fatigue, fear, sadness, anger, anxiety, panic will accentuate your pain. Also the cold as well as burning things. Unlike them, what is soft will relieve your pain…
>
> Don't take too many analgesics because the sleepier you'll feel, the more your muscles will tense. The brain takes it as a signal, like, saying: "Beware! I won't let go of anything!" Have you been advised to take cortisone in low dosages? On my face it works well but on my legs it never led to any results.
>
> Good and sweet night.] (*Oan48ky*, March 4, 2015)

The first paragraph of this comment shows that *Oan48ky* feels solidary with *carmentina* based on important similarities: their diagnoses of bipolar disorder and of trigeminal neuralgia, and the shared embodied experience of the terrible pain inflicted by the second. It also highlights the affective labor this contributor performs to help alleviate *carmentina*'s state, as she encourages and reassures her, while also expressing empathy. In the last part of the first paragraph and the second paragraph *Oan48ky* enacts solidarity by advising *carmentina* on the emotional and physical states that she should avoid, to better manage the pain. In so doing, she also enacts lay expertise, as she combines personal experiences with medical insights, and seeks to manage *carmentina*'s expectations by warning about the limited effectiveness of certain approaches. This comment further shows the emotional cost that reading about *carmentina*'s experiences poses for *Oan48ky*, as she is not only reminded of her own suffering, but is confronted with a vivid description of the pain experienced by an online contributor she has grown attached to.

5.7 Digital biocommunities and their roles

Whereas in the previous chapter I have shown that the internet has contributed to the development of a new form of individualization, the exchanges described above indicate that it has also facilitated the coming into being of a new type of collectivity. By considering how people diagnosed with bipolar disorder interact with each other online and the solidaristic practices they engage in, I argue that they contribute to the development of digital biocommunities. I understand digital biocommunities as new subgroups, based not only upon a common diagnosis, life circumstances, experiences, perspectives, and values, but also on similar engagements with the technologies of fora. This came to the fore in the online exchanges discussed above, where the most active online contributors on the fora shared numerous similarities, ranging from their age and gender, to common health issues, hobbies, and family circumstances. At the core of these communities are often a small group of dedicated online contributors, as it was not by chance that the reactions of *polarmouse* or *paige14* were quoted multiple times here. Such contributors participate intensively online, they interact frequently with each other, but also assume the position of hosts, as they welcome newcomers, make them feel at ease, and answer their questions. This was also the case for the exchanges studied on the two threads on the French forum, where despite the greater number of contributions, 10-12[16] contributors were particularly active and seemed to know each other very well, whereas the rest either joined at a later moment or contributed less intensively.

The feelings of belonging to the same digital biocommunity were highlighted by online contributors through specific engagements with the online affordances at their disposal on the forum. For instance, in order to motivate and encourage each other, *jechoisislavie* mentioned that all contributors should be proud of themselves and of what they had achieved; that they were brave warriors. This idea became quite popular for a short while, leading a subgroup of online contributors, who were most frequently in

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[16] Keeping track of the precise number and identity of contributors was not possible, as the data were not collected in real time, and online contributors changed their usernames with varying frequency, as a result of personal preferences or even online bullying.

touch with each other, to replace their regular profile photos with avatars with warrior themes. One of them even collected various images on this topic and made them available in a separate folder, thereby enabling other contributors on the thread to replace their profile photo in a sign of solidarity, if they wanted to. This shows not only the feelings of community that emerge among certain online contributors, but also the fact that they develop creative ways to make such feelings visible through their engagement with the various affordances offered by the fora.

In the previous sections I have highlighted some of the similarities that prompt online contributors to enact solidarity, and have shown that solidarity and lay expertise are closely related, as solidarity and lay expertise are either co-enacted or lay expertise appears as the result of specific enactments of solidarity. In this section, I want to delve deeper into the relationship between solidarity and lay expertise by highlighting how online contributors combine epistemic practices with affective labor to assist other members of their digital biocommunities.

5.7.1 (Self)knowledge

Digital biocommunities contribute to the development of lay expertise by facilitating the accumulation of personal insights in an environment where individuals feel safe and at ease. Whereas in situations where people are on their guard or where they believe they will be held responsible for certain behaviors, they tend to provide less information and of a more general character, the development of digital biocommunities and the feelings of shared intimacy that characterize them, prompt online contributors to give more detailed and personal information about themselves. Affective labor takes in such instances the shape of comments which help maintain and further communication, as online contributors continue to update others about their personal experiences with bipolar disorder in light of specific similarities. In so doing, they attempt to articulate the experience of living with this condition and to contribute together to the development of a more comprehensive account of the challenges it poses to one's life and to one's understanding of oneself. To help maintain communication, contributors have to make sure that the insights they provide are considerate enough of the situations described by others, they need to show that they take into account the comments they receive from others, and that they are respectful and appreciative of other people's opinions and experiences.

The exchanges enabled through such affective work allow online contributors to enhance their self-knowledge, to acquire a better understanding of the extent to which certain behaviors are triggered by bipolar disorder or are the result of other factors. Online contributors can thus better understand the development of a depressive episode, or they can evaluate how correctly they assess their states by tracing the content of their posts in time and by carefully considering the descriptions they provide. The following quote is telling in this sense:

fillmore
7I370S !!!!!!!!!!
Profil : Doctinaute de diamant

1. Posté le 22/01/2015 à 18:07:48
2.
3.

ben j'aarive a ne pas sortir...mais on dirai un lion en cage...

l'avantage c'est que depui que je ne suis plu au centre ville je ne peu plus sorti a pied au bar du coin...

mais bon j'ai l'impression que ces dernieres semaine c'est moins pire en bas, donc ca devrai etre moins pire en haut...

quoi que quand j'y pense j'etais mal au point de plus venir ici ...

c'est fout ce qu'on oublie au fur et a mesure

tu t'occupe comment du coup??

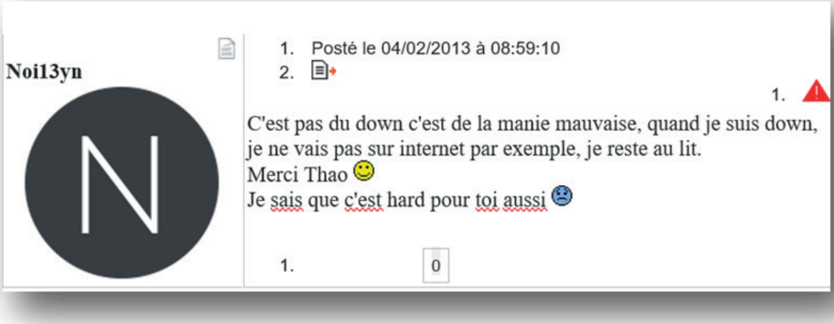
Doctissimo

0 1 2 3 4 5 6

se : open de france c'etait il y a 4 ans 2 mois et 23 jo

USERNAME	FORUM CONTRIBUTION
fillmore	well, I manage to not go out anymore…but I look like a caged lion…. The advantage is that since I no longer live in the center of the city, I can no longer walk to the bar at the corner of the street… But anyways, I have the feeling that over the last weeks it's been less bad going down [becoming depressed], so it should be less bad going up [becoming manic] Though when I think about it, I was in such bad shape that I didn't come here anymore… It's crazy how much we forget as time goes by… What are you up to now?

fillmore uses here her online presence as a tool to evaluate the severity of a depressive episode she had just experienced. While the first lines indicate that she was inclined to settle for a less negative evaluation of her lived experience, the realization that she could not even join the forum makes her reconsider, as the fourth paragraph shows. This reveals the considerable degree to which *fillmore* has integrated the forum in how she experiences her condition as well as the strength of the social bonds she has developed with the other contributors. In other cases, online contributors used their overall online behaviors as indicative of their health state, as can be seen below:



Noi13yn

1. Posté le 04/02/2013 à 08:59:10
2.

1.

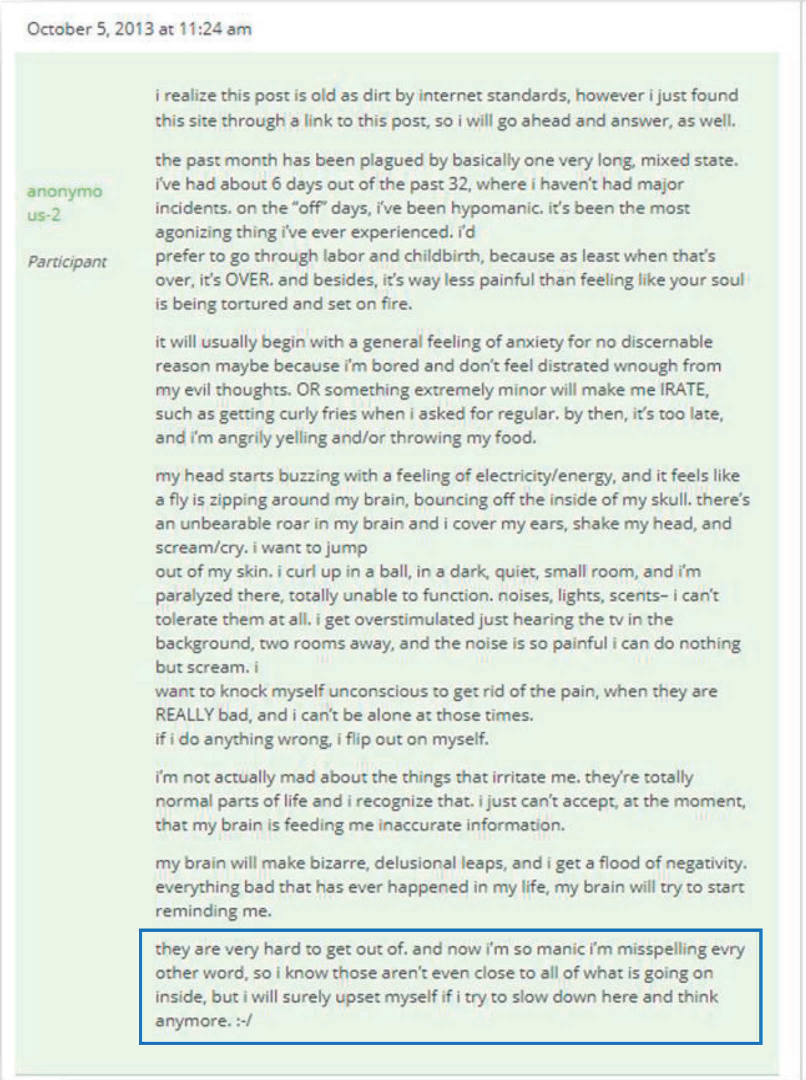
C'est pas du down c'est de la manie mauvaise, quand je suis down, je ne vais pas sur internet par exemple, je reste au lit.
Merci Thao 🙂
Je sais que c'est hard pour toi aussi ☹

1. 0

USERNAME	FORUM CONTRIBUTION
Noi13yn	It's not a down [depressive episode], it's a bad case of mania. When I'm down [depressed], I don't go online, for instance, I stay in bed. Thanks Thao 🙂 I know that it is hard for you too 🙂

This excerpt reveals that *Noi13yn* distinguishes between a depressive and manic episode based on his online presence. The last two lines reveal the gratitude he feels towards *Thao* and the support she has provided him with on the forum. They also indicate that such gratitude is shaped by the knowledge that these solidaristic practices are difficult when one is not well oneself. This comment also highlights the importance of a shared idiom of practice, since *Noi13yn* uses emoticons to indicate how he feels about the content provided in the last lines and expects *Thao* to correctly understand them. Thus, while the latter's support gives him reason to smile, to be joyful, the acknowledgement of the fact that she is also going through a difficult moment is accompanied by a particular emotional response, rendered in a simplified fashion through the sad, blue emoticon. This also points to another important function online contributors fulfill for each other, which is to authenticate individual experiences by recognizing them, by showing that they are familiar with (some of) the experiences described by others.

By developing digital biocommunities, online contributors increasingly relate to the digital technologies they use as particular means to act upon disease. As already indicated in chapter 3, through their online affordances, blogs and fora allow for the longitudinal accumulation of insights in the same space. Since online contributions to the same forum thread are preserved in the same location and are accompanied by details regarding the time and date where they were made, it becomes easier for people diagnosed with bipolar disorder to re-read the various comments they have made over a long period of time, and to discern specific patterns which may help them better identify triggers for certain mood episodes or improve their assessment of the mood state they experience. From this point of view, their online contributions may come to function as a form of online diary or as a mirror into their behaviors, thoughts, and emotions. The following post is illustrative in this sense, as *anonymous-2* provides a very thick description of the experiences she has during mixed states.



October 5, 2013 at 11:24 am

anonymous-2

Participant

i realize this post is old as dirt by internet standards, however i just found this site through a link to this post, so i will go ahead and answer, as well.

the past month has been plagued by basically one very long, mixed state. i've had about 6 days out of the past 32, where i haven't had major incidents. on the "off" days, i've been hypomanic. it's been the most agonizing thing i've ever experienced. i'd
prefer to go through labor and childbirth, because as least when that's over, it's OVER. and besides, it's way less painful than feeling like your soul is being tortured and set on fire.

it will usually begin with a general feeling of anxiety for no discernable reason maybe because i'm bored and don't feel distrated wnough from my evil thoughts. OR something extremely minor will make me IRATE, such as getting curly fries when i asked for regular. by then, it's too late, and i'm angrily yelling and/or throwing my food.

my head starts buzzing with a feeling of electricity/energy, and it feels like a fly is zipping around my brain, bouncing off the inside of my skull. there's an unbearable roar in my brain and i cover my ears, shake my head, and scream/cry. i want to jump
out of my skin. i curl up in a ball, in a dark, quiet, small room, and i'm paralyzed there, totally unable to function. noises, lights, scents– i can't tolerate them at all. i get overstimulated just hearing the tv in the background, two rooms away, and the noise is so painful i can do nothing but scream. i
want to knock myself unconscious to get rid of the pain, when they are REALLY bad, and i can't be alone at those times.
if i do anything wrong, i flip out on myself.

i'm not actually mad about the things that irritate me. they're totally normal parts of life and i recognize that. i just can't accept, at the moment, that my brain is feeding me inaccurate information.

my brain will make bizarre, delusional leaps, and i get a flood of negativity. everything bad that has ever happened in my life, my brain will try to start reminding me.

they are very hard to get out of. and now i'm so manic i'm misspelling evry other word, so i know those aren't even close to all of what is going on inside, but i will surely upset myself if i try to slow down here and think anymore. :-/

Some of the comparisons she draws upon are gendered and invoke painful, raw experiences, which help to convey convincingly the suffering she feels. This enables readers who may not have experienced mixed states, but who may have undergone labor and childbirth to better understand her. While the detailed description of her reactions and stressors suggests that *anonymous-2* is aware of her behavior during such states and has reflected on the (in)validity of the triggers, the last part of her post shows that she evaluates her online contribution in order to better assess her state. While this may have prompted her to take certain actions, the availability of her post online makes it possible for this contributor to return to it when she may feel better in order to acquire further insights into her states and behaviors, and learn how to better manage them. At the same time, such detailed descriptions may help others better recognize some of the experiences they undergo as indicative of a particular episode, thereby potentially facilitating the development of appropriate and timely reactions. In general, people diagnosed with bipolar disorder come to know how their behaviors and actions look like when experiencing a depressive or manic episode from the accounts of witnesses, family members and friends who are willing to share them. Online contributors on fora can return, however, to the contributions they have made at specific moments in time, to see for themselves what topics they take up, how frequently and extensively they post, and how they engage with others.

The use of a shared idiom of practice plays an important role in this sense, as it helps online contributors better assess their own states or those of others based on the appearance of "foreign" elements or on the "deviant" use of certain online affordances. For instance, in a context where forum interactions tend to be rather short and succeed each other quickly, the provision of very long comments, sometimes stretching over six-seven pages when transferred to a Word document, is sometimes seen as indicative of a manic episode, as the example below will show. Similarly, very short replies or the absence of any emoticons across several contributions provided by the same person is seen as a mark of flat affect, which characterizes depressive episodes. By considering the content they provide in such instances or in the period before and after specific episodes, online contributors can acquire a more thorough understanding of the elements that may trigger certain reactions and of the factors that announce the upcoming onset of a depressive or manic episode. They can subsequently use such insights in order to avoid certain products, behaviors, areas, and people or to get in touch with medical professionals in time. This way, people's ability to manage bipolar disorder is enhanced through the narratives, thick descriptions, and dialogue that fora allow for. Online contributors can further their self-control and better navigate daily life through the practices of self-revelation/clarification and collective consultation they thus engage in.

Through their frequent and long-lasting interactions, not only do members of digital biocommunities come to know themselves very well, but they also acquire substantial knowledge of others. For instance, in several cases, online contributors could determine when someone else was experiencing a specific mood episode based on their online contributions, as the following excerpt illustrates:

> tina...t'es en forme ou cest juste une effet d'optique de la toile???
>
> [tina…are you in good shape or is it just an effect of the screen???] (*fillmore*, February 3, 2015)
>
> l'effet d'optique traduit une réalité vraie ! je suis en up durable ; je commence même à penser que c'est mon état normal et que rien ne viendra le bouleverser 😡. (😕)...
> [the optical effect conveys a true reality! I have been in an up [in a manic state] for some time now; I'm even starting to think it's my normal state and nothing will upset it 😡 (😕)...] (*carmentina*, February 3, 2015)

This exchange also shows that the knowledge online contributors acquire about each other and about themselves as members of a particular digital biocommunity is underlined by the development of a shared idiom of practice. This is revealed here through the use of the euphemism "to be in good shape" to denote a manic state, which *carmentina* correctly understands, as well as through the specific use of emoticons. The Red Face emoticon is characteristic for *Doctissimo*, and is used to convey negative emotions, such as anger and exasperation (Lombart, 2018). The second emoticon conveys feelings of being puzzled, of not knowing what to do. The order of these two emoticons combined with the fact that the second one is provided between brackets help reveal the function each emoticon is meant to fulfill. The Red Face emoticon is expressive of *carmentina*'s emotions in regard to her mood state, her frustration at the fact that she knows that the feelings she experiences are not accurate, yet she cannot do away with them. The second emoticon fulfills a relational function, it shows that *carmentina* uses it to connect with *fillmore*, to expresses regret about the state she finds herself in and about the impact it may have upon her online friend.

Not only do online contributors inform the other members of their digital biocommunities about the ways in which their behaviors appear to them, but they also actively ask others to give them advice regarding their own states, when they are uncertain about them, as the excerpt below indicates:

> en faveur du up :
>
> je me lève tous les jours vers 4 h 😡
>
> j'ai commencé à mettre plein de bijoux alors que depuis des mois je n'avais que mon alliance et celle de feue ma maman 😡

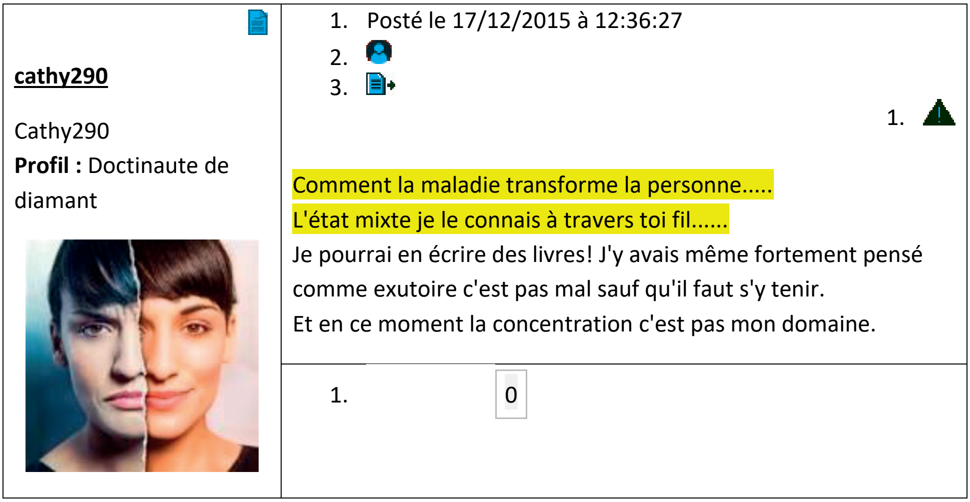
> en défaveur du up :
>
> je ne me sens pas excitée 🙂
>
> je ne fais pas d'achats compulsifs 🙂
>
> je ne suis pas agressive 🙂
>
> [in favor of the up [manic episode]:
>
> I get up every day around 4 pm 😮
>
> I started to put on a lot of jewels whereas for months I had only been wearing my wedding ring and the one of my deceased mother 😮
>
> against the up [manic episode]:
>
> I don't feel excited 🙂
>
> I don't do compulsive shopping 🙂
>
> I am not aggressive 🙂] (carmentina, 30/08/2015)

This quote shows that *carmentina* interpellates the other online contributors as experts, who not only have substantial experiential knowledge on bipolar disorder, but also know her very well. *carmentina* invites them to enact lay expertise by replicating to a certain extent the activities of medical professionals when seeking to establish a diagnosis. Thus, she describes her online and offline behaviors as clues which they can use together towards the correct identification of her state. To assist the other online contributors, she places her behaviors in context, and she provides information about their frequency and about her own emotions in regard to them. By sharing one's experiences, symptoms and behaviors, people can reflect upon them in dialogue with similar others. This can further their self-knowledge, as aspects of the self which may be opaque or ambiguous to the individual diagnosed with bipolar disorder are clarified through such interactions. The following reaction is also illustrative in this sense:

> Thank you for your personal experiences you have helped me understand a lot more about myself. I only wish my clinical psych was as clear about this as the information I've managed to understand here. (*biped*, April 17, 2016)

This reaction is important because it suggests that the self-insights *biped* acquired online were informed by the experiential knowledge shared by people diagnosed. Furthermore, this contributor acknowledges the effectiveness of the lay expertise enacted by online contributors, as he credits them to having helped him better understand this condition than his medical professional had been able to.

The personal insights people diagnosed with bipolar disorder share online, their detailed descriptions of their states and behaviors also enable others to increase their knowledge about this condition in regard to aspects that they do not personally experience, as the quote below illustrates:



cathy290

Cathy290

Profil : Doctinaute de diamant

1. Posté le 17/12/2015 à 12:36:27
2.
3.

1. ⚠

Comment la maladie transforme la personne.....
L'état mixte je le connais à travers toi fil......
Je pourrai en écrire des livres! J'y avais même fortement pensé comme exutoire c'est pas mal sauf qu'il faut s'y tenir.
Et en ce moment la concentration c'est pas mon domaine.

1. 0

USERNAME	FORUM CONTRIBUTION
cathy290	How the illness transforms a person…. I know the mixed mood state through you fil…. I could write volumes about it! I had even strongly thought of it as an outlet it's not bad except that you have to stick to it. And at the moment concentration is not one of my strengths.

Through her frequent interactions with *fillmore*, *cathy290* has come to know her and her mood states so well, that she believes she would be able to provide rich accounts about mixed episodes. This shows that while no individual diagnosed with bipolar disorder can have experiential knowledge about all the symptoms of this condition, through their frequent interactions with other people diagnosed, online contributors come to develop lay expertise about it and to enrich their personal knowledge through first-hand accounts acquired from others. This is important, because it shows that people are not only interested in understanding the individual manifestations of their condition, but they want to acquire a thorough understanding of bipolar disorder, which is only possible by accumulating different types of knowledge and by relating their experiences to those of others.

The examples discussed above have shown that fora represent new sites for both knowledge acquisition and production. Thus, online contributors develop a better and more complex understanding of bipolar disorder by learning from other people's experiences. At the same time, online contributors diagnosed with bipolar disorder also contribute to the development of new insights, as intensive interactions with others allow them to bring in relation to bipolar disorder aspects of their behaviors they had not previously considered to be shaped by it, or to identify certain patterns which enable them in time to better manage this condition. Whereas in chapter 3 I have showed how people diagnosed with bipolar disorder could contribute to the development of new insights about the effects and side-effects of medications through their online engagements on blogs and fora, here I show that fora can be used to enhance the knowledge online contributors acquire about themselves and others in regard to the manifestations of this condition and how it shapes their personhood.

5.8 Discussion

This chapter has shown that solidarity and lay expertise are tightly linked, as people diagnosed with bipolar disorder engage in sharing practices to benefit others with whom they share important commonalities and in so doing also enact lay expertise or contribute to its collective development. This indicates that despite individualizing tendencies in personalized and precision medicine, bipolar disorder should be understood in relational terms, as online contributors shape its meaning together with family members, friends, other people diagnosed, and medical professionals. At the same time, the practices described in this chapter have shown that online contributors do not focus so much on the distinctions between themselves and others, but try to identify common elements. These can vary in terms of their specificity, ranging from a common vulnerability due to this diagnosis, which is applicable to all, to more particular aspects, such as certain symptom experiences, life circumstances, personal preferences and hobbies. To account for this innovative coming-together, I have put forward the concept of digital biocommunities to denote the development of (sub)groups based on numerous commonalities of experience and similar engagements with the technologies of fora.

The development of digital biocommunities indicates that people can choose to foreground what they hold in common in relation to their health rather than focusing upon what makes them different, and that the recognition of similarities prompts them to assist others at a personal cost. From this point of view, digital biocommunities bear some resemblance to the self-help literature, which in the past has facilitated the development of a common identity among people diagnosed with contested conditions, such as fibromyalgia syndrome (Barker, 2002). Even though bipolar disorder is a medically recognized condition, recent medical perspectives have focused on the differences between people diagnosed with it. For instance, Wium-Andersen and colleagues (2017:13) stated that "[t]o provide personalized medicine in target areas such as diagnostics, treatment selection, and response, assessment of risk of side-effects, and prediction of illness, the clinician relies on tools to help differentiate patients from one another." While the focus on differences rather than on similarities among people with the same diagnosis may threaten to "de-solidarize" them, digital biocommunities represent one of the ways in which such tendencies have been recently countered. Thus, the online contributors studied here shared the health information and experiential knowledge they had acquired as acts of solidarity with others diagnosed with bipolar disorder and with whom they shared additional commonalities. Through their online interactions, online contributors brought together, compared and reflected upon numerous distinct, disparate, individual experiences of living with bipolar disorder. In so doing, they contributed to the development of lay expertise on this condition, as a more unified and comprehensive image of bipolar disorder and of the ways in which it can manifest itself at the personal level emerged as a result of frequent online exchanges. The well-being of online contributors was this way furthered, not only because they became more knowledgeable about their condition, but also because they became aware that the risks and vulnerabilities it triggers are shared by all people diagnosed with it.

It is noteworthy that the development of digital biocommunities takes place in a context when in both the U.S. and France the number of self-help and support groups, described in more detail in chapter 1, has been increasing (Girard, 2008). For instance, while the law stipulating the creation of mutual help groups — *Groupes d'Entraide Mutuelle* (GEMs) — in France was adopted in 2005, by 2008, 300 GEMs had developed (Girard, 2008), while in 2016, 430 GEMs were counted throughout the French territories (CNSA, 2016). Similarly, a national survey conducted in the U.S. in 2002 revealed that there were 7,467 organizations led by and for consumers of mental health services and their families, a substantial number compared to the 4,546 traditional, professional-led mental health organizations (Goldstrom et al, 2006). Through their focus on furthering the well-being of people diagnosed and on providing them with emotional support and information, digital biocommunities resemble many of these self-help and support groups, which may indicate a growing need among people diagnosed to come together, share experiences and support each other. From this point of view, these findings are in line with those presented in other studies on the online interactions of people diagnosed, which have shown that online communities share with their offline predecessors similar objectives, work practices, modes of approach, and orientation towards cognitive resources (Akrich, 2010).

The more intense participation on *Doctissimo* may be explained by putting the online solidaristic practices that members of digital biocommunities engage in in the broader social and cultural context from which they emerged. While self-help groups have been historically less influential in France than in the U.S., solidarity is considered by many in France to be a national value. The importance of this particular value might be the reason why on both threads on *Doctissimo*, French online contributors engaged in more numerous and frequent exchanges to support others in need. The idea that cultural and social differences play an important role in explaining such distinct online behaviors was further reinforced by the fact that on two other American fora, which were consulted only to compare the number of participants and their interactions, few threads exceeded 30 comments, let alone reach hundreds or thousands. Future studies are needed to acquire a better understanding of what informs such differences in online participation and support between contributors from the U.S. and France. It may be particularly fruitful to compare the online landscape available for both countries, as infrastructural, economic and institutional factors may have contributed to a more dispersed online environment in the U.S. and to a more centralized one in France.

Since the development of digital biocommunities was noted in a context where the growth of offline self-help groups has been stimulated in both countries, it is worth considering how the online exchanges described in this chapter may differ from offline interactions. For some participants, one of the important advantages of digital biocommunities is increased convenience, as they may easily identify others with whom they share important similarities, due to the availability of personal information in easily accessible and recognizable spaces on the fora or based on the profile images and signatures of individual contributors. At the same time, they can read other people's posts and react to them at any place and time, and the lack of face-to-face interactions might be preferable for people who find physical proximity more difficult to handle or who are worried about being stigmatized in their daily life if many people come to know about their diagnosis. The ability of fora to function as public diaries, the seeming permanence of the information made available there might explain to a larger extent, however, the development of this new type of community, as people diagnosed can go back to their own contributions, reflect upon them, and acquire better insights into themselves and into the ways in which they behave when experiencing specific mood episodes. Furthermore, unlike offline encounters, where no (detailed) records of the interactions are preserved, such online exchanges enable people to develop self-knowledge in ways which make them more aware of the influence of other people and of the artefacts they use.

According to Prainsack and Buyx's (2017), background conditions play an important role in furthering or deterring solidaristic practices. Based on the data analyzed here, it seems that fora allow solidarity to flourish, as common knowledge grows gradually among a small group of participants on a thread, which allows them to identify multiple relevant similarities and to develop a feeling of community. More research is, however, needed in order to better understand what role the different affordances and design of fora play in such developments. As some of the examples provided here have shown, solidarity can also develop as people invoke commonalities to distinguish themselves from others. Building upon Sharon's (2017) suggestion, further research is therefore also needed in order to understand how online affordances encourage the development of specific types of solidarity. Since the authorities have increasingly focused on the internet to provide cost-effective care, such insights might inform the design of future online platforms, which are intended to further solidaristic practices among people. They might also be used by platform owners to implement mechanisms to avoid the development of exclusionary solidaristic practices, which may harm or disrespect others.

The findings presented in this chapter also revealed the close relationship between solidarity and lay expertise, as people diagnosed with bipolar disorder often engaged in solidaristic practices by sharing their experiences and insights, which contributed to the development of collective knowledge on this condition and also helped online contributors to position themselves as lay experts in certain contexts. Such instances revealed an important tension between one's temporary position as an expert and lay expertise as a form of substantial practical knowledge, which supersedes any one individual. This is important because it shows that expertise comes into being as different stakeholders interact and shift positions within a complex ecosystem, consisting of different technologies, standards, forms and levels of knowledge, cultural norms, social provisions, regulations, and individual values and preferences. The findings in this chapter also showed that the mobility through which expertise is developed is circumscribed by the characteristics of the system and the (inter)dependencies that develop among different stakeholders. Thus, in the accounts described in this chapter, lay expertise was developed as contributors diagnosed with bipolar disorder within a particular healthcare system came together through interactions which were informed by specific cultural norms and perspectives on this condition. In their online exchanges, online contributors alternated, based on the topic discussed and on their needs, between the position of expert and that of information- and advice-seeker, they took turns at being "patients", "pharmacists", "therapists", "doctors", "mothers", "employees", "passionate horse-riders", and “travelers”. Lay expertise thus emerges as a 3D-puzzle, which takes time and effort, and requires the dynamic engagement, adaptability, and affective labor of many people.

This chapter has also shown that new knowledge is produced in the process of or as a result of interactions meant to assist people with whom online contributors share important similarities. While this is in line with practices described by scholars who have studied patient associations (Rabeharisoa et al, 2013), it is nonetheless relevant in a context where knowledge is increasingly referred to as a resource that can be privately owned (Newell, 2015), and is thus more often brought in relation with other values, such as competitiveness or efficiency. At the same time, the excerpts provided have highlighted the affective labor online contributors engage in in such instances, as they not only provide information about this condition and strategies to better manage it, but they also pay attention to the emotional state of the person asking for information or support, and are careful to phrase their reactions in supportive and motivating ways. For knowledge to be shared, circulated, and produced, it is not enough for people diagnosed to identify relevant similarities, but they also need to be able to do the emotional work required when interacting publicly with multiple individuals. Furthermore, the development of lay expertise depends on the ability of online contributors to appeal to the considerations, emotions, and perspectives that a specific person or more people, depending of their scope, would be open to, which requires additional care, time, and effort. This highlights the important role affective practices and engagements play in the production of knowledge, even though these are aspects which have been thus far neglected in social studies of science.

The interactions described among online contributors suggest that digital biocommunities can have positive effects, as they can bring people together and help them enrich their knowledge of bipolar disorder and better manage it at the level of daily life. Nevertheless, it is important to bear in mind that solidarity is not in itself a positive value (Dean, 1995). As people come together with others with whom they share important similarities and are willing to incur costs in order to assist them, they also distinguish themselves from those with whom they do not share such similarities. Such tendencies could also be noted in this chapter, as some online contributors distinguished in essential ways between people who were diagnosed with bipolar disorder and those who were not. While such processes of inclusion and exclusion may not be prevented, for digital biocommunities to continue to have positive effects, it is important that their members reflect upon the criteria they use to include and exclude others, and upon the consequences such practices may have. This could be achieved, for instance, by providing online contributors with the option to receive weekly or monthly overviews of the contributors they have most often been in touch with, of the threads they have been most active on. It should be up to the contributors to decide whether such information will be collected to begin with, and whether it will be preserved and used for other reports or whether it will be deleted once the contributor has seen it. Another option would be to periodically provide online contributors with a list of threads they have not participated on, leaving it entirely up to them to decide whether or not to take a look at them and contribute, or to remain in spaces on the platform where they feel comfortable. From the data I collected, it was obvious that some online contributors ventured more often than others onto other topics, and were often confronted with difficulties due to a different idiom of practice, different interactional goals and different types of humor, for instance. At the same time, the multiple, dynamic character of the digital biocommunities that one may be a part of may serve to prevent the reification of certain forms of difference, thereby partially addressing this issue.

The solidaristic practices described in this chapter were identified at a time when the pronounced personalization and individualization of responsibility brought about by personalized and precision medicine have led many scholars to approach solidarity as a value that is under threat and in need of protection (Aarden et al, 2010). The resilience of solidarity in this context suggests that it is a very important value to people, who find solace in knowing that they are not alone in experiencing specific issues, but that there are others who struggle like them. The concept of digital biocommunities suggests that as people come together based on increasingly more specific commonalities of experience, they might form part of multiple dynamic (sub)groups, depending on the similarities they focus upon and the solidaristic practices they engage in. This has consequences for the ways in which personhood and "personalized" are understood, as it suggests that they are defined and re-defined through social interactions and practices which are meaningful to people diagnosed. The findings presented here have also revealed the feelings of well-being that people experience when they come together with others with whom they share important commonalities. By enacting solidarity with other online contributors, people diagnosed with bipolar disorder could temporarily position themselves as knowledgeable, capable, and supportive rather than frail, vulnerable, and in need of help. Hopefully, through their multitude and diversity, the development of digital biocommunities will provide people with bipolar disorder at least with temporary settlements, with safe havens where they can feel at ease, where they can become better aware of their talents, strengths, and knowledge, and of the important values they uphold as they share them with others.

Chapter 6

Expertise in the age of big data

CHAPTER 6

6 EXPERTISE IN THE AGE OF BIG DATA

In the previous chapters, I explored how expertise about bipolar disorder is enacted on American and French online platforms. This study was motivated by important debates about the meaning and the effects of major transformations that expertise has undergone in Western societies. Over the last decades, expertise has come to occupy a rather paradoxical position. On the one hand, we are surrounded by *more* expertise, because ever more domains of our lives have come under the authority of "experts", and because expertise has been increasingly claimed by "non-experts", by people lacking official accreditations. On the other hand, the right and authority of experts to make decisions that impact upon the lives of many and the grounds upon which such decisions are made have been called into question, as the rise in anti-elitist and populist feelings over the last decade indicates. We live, therefore, at a time, when expertise is both ubiquitous and very much challenged. The internet has played an important role in these developments, as it has provided new avenues for the production, dissemination and evaluation of knowledge. Since this medium has been widely used by a broad range of stakeholders in the field of mental health, throughout this dissertation I have scrutinized the different ways in which it has shaped the enactment of expertise about bipolar disorder.

The use of the internet in mental healthcare has given rise to numerous fears and expectations. Some have hailed this medium's potential to help improve the accessibility and affordability of mental health therapies and have also welcomed the possibility it affords people diagnosed to come together and exchange insights with others with the same diagnosis. Others have worried about the varying quality of online mental health-related information and about the ways in which such insights may affect relations between medical professionals and people diagnosed, which have been rather strained historically. These fears and hopes are to a certain extent well-founded, yet they neglect the multiple, dynamic character the internet can have as well as the different forms of engagement users can take up online, depending on their personal interests, skills, goals, as well as on the social and cultural perspectives which shape their understanding of specific mental health conditions. In this dissertation, I have tried to reconcile the agency of users with a perspective which sees online technologies as value-laden and capable to actively influence people's behaviors. This way I have been able to compare the ways in which different stakeholders seek to make their expertise manifest by using different online technologies and I have scrutinized how the design and online affordances available on different online platforms shape such enactments. I have also investigated the transformations that such online engagements may lead to in the relations between people diagnosed and medical professionals, and have probed the individualizing or collectivity-generating effects the internet can have in regard to the online enactment of expertise. Furthermore, I have also studied how different cultural norms and values inform these transformations.

The main finding of this dissertation is that the online enactment of expertise is not a straightforward process by which offline practices, tools and approaches are transferred online, but involves additional skills and complex negotiations, which sometimes lead to unexpected configurations. Despite expectations that the availability of health-related information would lead to patient empowerment and would allow people diagnosed to re-position themselves in relation to medical professionals, the findings presented here have revealed a more complex picture, where individuals diagnosed with bipolar disorder can become highly influential through their skillful use of the internet and by developing and cultivating important alliances with "traditional" experts. Contrary to expectations that the focus on "radical" difference in personalized and precision medicine would lead to increased individualization, online contributors diagnosed with bipolar disorder enacted solidarity with others with whom they shared numerous similarities, which prompted them to engage in epistemic practices as well as affective labor. These findings led me to put forward a new conceptualization of expertise, as a practical and collective achievement, realized through coordination and affective labor among stakeholders who occupy multiple and shifting positions within a complex ecosystem.

Each of the empirical chapters has highlighted different ways in which expertise on bipolar disorder was enacted online by various stakeholders. In this chapter, I bring these findings together and consider what they can tell us about the meaning and relevance of expertise in the context where promises generated by big data analytics suggest that substantial knowledge no longer describes (solely) a set of human capabilities and may no longer require human intervention in order to be applied in a variety of contexts. Before doing so, I highlight what the findings presented in the empirical chapters mean in relation to each of the research questions this dissertation has addressed and provide some suggestions for future research.

6.1 The online enactment of expertise about bipolar disorder

In this dissertation, I have studied how expertise about bipolar disorder is enacted on American and French online platforms, at a time when the role and legitimacy of expertise have been challenged and when the internet has been increasingly approached either as a quick technological fix or as a postmodern version of Pandora's box. Thus, on the one hand, this medium has been hailed as holding, leading to, or being the solution to problems of various sorts. On the other hand, it has been perceived with growing apprehension as having the potential to unleash all sorts of evils upon humanity, especially by fostering distrust among people and by heightening suspicion about any attempts at unified conceptualizations and about the meaning and authority of organized forms of knowledge. To investigate how the internet has shaped the enactment of expertise about bipolar disorder, I have focused on four sub-questions. First, how do different stakeholders engage with online technologies to enact expertise about bipolar disorder? Second, how does the internet contribute to people diagnosed re-positioning themselves in relation to medical professionals? Third, how do cultural markers shape these online enactments? Finally, what individualizing or collectivity-generating effects does the internet have in relation to the online enactment of expertise about bipolar disorder? In answering these questions, I have studied the online contributions of two main types of stakeholders: governmental agencies and people diagnosed. In what follows, I discuss the findings for each sub-question in the order in which they are mentioned here.

6.1.1 Different stakeholders' use of the internet

One of the unambiguous conclusions of this study is that different stakeholders used online technologies differently, and that the choice thereof was not only informed by the resources at their disposal, but also by their goals and priorities. Thus, the analysis revealed that even though the *National Institute of Mental Health* (NIMH) and *La Haute Autorité de Santé* (HAS), the two governmental institutions studied in this dissertation, have vast financial and technical resources at their disposal, they are reluctant internet users, who have opted for non-interactive platforms and for conservative online technologies. Such an approach has allowed them to push to the backstage perspectives and research orientations that are no longer popular and it has also enabled them to obscure from view the disagreements and struggles between different medical professionals who study or provide medical care for this condition. Furthermore, this choice for noninteractive platforms has allowed them to share their perspectives about bipolar disorder authoritatively and without directly addressing the challenges brought to psychiatry by people diagnosed, their families, and even medical professionals. While both governmental agencies have opted for noninteractive platforms, they have used different online tools, which are better aligned with their main goals and audiences. For instance, through the affordances available on the pdf files HAS has provided, such as the audio option and the ruler, this governmental agency has used its platform for very specific educational purposes, meant to facilitate information retention and decision-making in clinical practice. The choice for noninteractive online platforms appears thus to be a pragmatic decision undertaken by bodies which need to provide guidance and some stability to facilitate medical practice above all else. This dissertation has shown that these governmental agencies have to consider the heterogeneity of the population they address in their online enactment of expertise about bipolar disorder online, but I had limited access to insights about the ways in which the information posted online is produced. From this point of view, studying how the work and interactions of those called to design and implement the therapies or initiatives put forward by these institutions are shaped by aspects of their personal identity, and how the latter affect the ways in which the users are envisaged would be a fruitful direction for future research.

Unlike the governmental agencies discussed, people diagnosed with bipolar disorder use blogs and fora, where they can share their doubts and insights, either by initiating forum threads or by commenting on blog posts or threads written by others. This allows for a bottom-up accumulation of perspectives and for a dialogical enactment of expertise, as various treatment experiences, the advantages and disadvantages of various therapeutic approaches, the results of self-experiments can be extensively discussed among numerous contributors. Whereas the people diagnosed studied in chapter 3 use the internet to share their treatment experiences and to acquire specific information, the online contributors studied in chapter 5 use fora to come together and support others with whom they share important commonalities. I have shown that how they engage with the affordances available on these online platforms plays an important role in the development of digital biocommunities, as it constitutes a relevant similarity and reinforces sharing practices among the members of this new type of group. This way members of such communities come to use these online platforms as public diaries, through which they and their readers can keep track of developments in their mental, physical, and emotional states.

The different reasons people diagnosed with bipolar disorder choose to use the internet also lead to different dynamics. In general, online contributors interested in specific information share their treatment experiences across one or several exchanges within a brief period of time and return sometimes after a long interval to share new insights. In contrast, people interested in developing closer ties with others put a lot of time and effort into sharing their experiences online and reacting to those of others, either on the main page of the fora and/or through private messages with specific contributors. Only a very limited number of medical professionals have shared their insights on the blogs and fora studied here, which has prevented the development of clear perspectives on how they use the internet to acquire or share information about bipolar disorder. Since the prevalence of this condition suggests that a considerable number of medical professionals must also be diagnosed with bipolar disorder, it would be interesting to find out more about their perspectives in this regard and on the ways in which they call upon their different types of knowledge to enact expertise about bipolar disorder online.

6.1.2 People diagnosed, medical professionals and the internet

The findings presented in this dissertation also indicate that the internet is not a neutral medium through which expertise about bipolar disorder can be enacted, but that it shapes in some notable ways the position people diagnosed can occupy in relation to medical professionals. Through the use of blogs and fora, people diagnosed with bipolar disorder are able to engage in processes of knowledge production about this condition, thereby acquiring more influence and agency. As discussed in chapter 3, through their online affordances which allow for the longitudinal accumulation in the same spaces of numerous insights, blogs and fora facilitate the development of what I have called "digitally-informed hypotheses" about the effects and side-effects of medications. This may have immediate empowering effects for individual users, by confirming the importance of their insights and thereby encouraging them to assume a more confident position in their interactions with medical professionals. In other cases, online platforms seem to represent therapeutic approaches in themselves, as getting in touch with other people diagnosed and talking to them about their issues is often framed as contributing to one's well-being and mental stability. Also from this point of view, the internet appears to empower some online contributors, as it assists them in developing more agency over bipolar disorder. If recognized by relevant others, such as family members, medical professionals, current or potential employers, this ability of people diagnosed to better manage their condition could, in turn, improve their quality of life by leading to more equal relations and more collaborative exchanges.

As people with different understandings of bipolar disorder, who have different relations with their medical professionals, different needs and possibilities in their daily life, come together online, even in brief exchanges, the internet may also have contributed towards a more open dialogue about this condition. In time, this may lead to the development of new standards to determine what accounts for reliable information at a more general level. Importantly, while at the moment the "digitally-informed hypotheses" described in chapter 3 require the assistance of medical professionals to become clinical evidence, in time this may no longer be necessary. As the integration of different types of data fueled by personalized and precision medicine may develop further, the insights provided by people diagnosed through their online interactions may come to be recognized as clinical evidence, even in the absence of significant interventions from medical professionals. Should this occur, it will be difficult to deny the contribution of blogs and fora in enabling people diagnosed with bipolar disorder to re-position themselves more authoritatively in relation to medical professionals, as they will have produced new knowledge online and will have thus shaped the prescription of treatment for this condition.

The findings in chapter 4 also show that while the internet does not always favor the powerful, only a small number of individuals are able to re-position themselves and to acquire a high standing. The two bloggers studied in this chapter have managed through the skillful use of this medium to become highly influential. Through their popularity, visibility, and credibility, Tracy and Fast not only shape the ways in which their readers understand and approach bipolar disorder, but also influence research agendas and the production of knowledge about this condition, as they engage in productive collaborations with medical professionals. The findings reveal, however, that thus far these bloggers have not used their standing to further democratize participation in the production of knowledge. Rather than promoting research projects developed by citizen scientists or various crowdsourced initiatives, Tracy and Fast inform their readers about projects undertaken by medical professionals with whom they are familiar, or with whom they have personally collaborated. Nevertheless, this may be an initial approach taken up in order to acquire sufficient legitimacy. In the future, Tracy and Fast (or others who also come to occupy similar positions of authority) may become more supportive of grassroots scientific initiatives and thus contribute to new types of collaborations between medical professionals and people diagnosed with bipolar disorder or other conditions. From a different point of view, through the efforts they make to familiarize readers with scientific methodology and through their advice on how to best approach medical professionals, these bloggers may, nonetheless, already help their readers develop more collaborative relations with the latter and may facilitate the participation of a greater number of people diagnosed with bipolar disorder in research.

The findings presented in chapter 3 and 4 indicate that forum administrators and blog authors can play an important role in regard to the type of information made available on their platforms. Studies focusing on different types of blogs and fora are needed to acquire a more detailed understanding of how blog authors and forum moderators/administrators influence the content of the reactions received. In this dissertation data were collected from blog posts and forum threads with many comments, thus the insights provided on the selected online platforms may be more representative of people's experiences with certain therapeutic approaches than others. Focusing on the content made available on online platforms with limited (public) interactions and comparing differences in online interactivity in relation to various forms of treatment would therefore be a promising avenue for future research. Furthermore, since the results presented here are based on the experiences of readers who were motivated enough to contribute online, they do not represent all people diagnosed with bipolar disorder. More studies are therefore needed to understand the perspectives of people who use interactive online platforms for information purposes but refrain from contributing and those of people who refuse to use the internet for health-related purposes or who do not have access to it. Studying the impact online contributions have on readers and how lasting their effects are among other online participants would also provide valuable contributions to the literature. To better understand how people diagnosed with bipolar disorder re-position themselves in relation to medical professionals through their use of the internet, offline ethnographic studies on how medical professionals make sense of such online engagements, on how online expertise is brought to medical settings and the consequences this has would be needed.

6.1.3 Cultural markers and expertise about bipolar disorder online

This study also shows that local norms and values play an important role in how expertise about bipolar disorder is enacted online. Content-wise, the differences between the contributions on American and French online platforms are largely shaped by the ways in which mental healthcare is organized in these countries and by the preferred scientific approach to bipolar disorder. Thus, differences in the insurance system lead to different uses and engagements with the technologies of online platforms. For (temporarily) uninsured American contributors, online platforms constitute valuable alternatives or stand-ins for medical professionals, as these contributors rely upon the advice of other people diagnosed to identify affordable and effective medications and to determine some alternative practices they can take up, to heighten their chances to remain stable. Furthermore, discussions about generic drugs and their different effects are very popular on American blogs and fora, but do not occupy a prominent position on French platforms. In contrast, many French contributors worry about overmedication in France, since surveys position France among the countries with the highest consumption rates in Europe. Another noteworthy difference concerns the social impact ascribed to bipolar disorder. Whereas most American contributors frame this condition as a disability which prevents them from gaining or maintaining meaningful employment, many French contributors are employed, at times in highly demanding positions.

The relations between medical professionals and people diagnosed seem fairly balanced on French platforms, with some contributors confessing to more strained relations and denouncing the practice of forced hospitalization, while many others express trust in their medical professionals and describe their interactions with them as collaborations, even though between unequal partners. In contrast, on American platforms there are more pronounced tendencies for people diagnosed to complain about the quality of medical care they receive, to highlight the lack of trust medical professionals display towards their experiences with medications. While some contributors explain such strained relations by invoking the close financial links between psychiatrists and pharmaceutical companies, there are also many who ascribe them to the different levels of expertise of different medical professionals. Furthermore, in the U.S., the antipsychiatry movement seems to have remained influential enough to be taken up on many of the blogs and fora studied. In France, psychoanalysis is still considered a possible therapeutic approach, making its presence felt through the use of its terminology in discussions about the causes of bipolar disorder and about the elements that may affect people's response to treatment.

There are also important differences regarding the preferred types of online technologies people diagnosed with bipolar disorder from these countries use. Whereas in the U.S., blogs acquire more readers and more comments, in France, fora are by far the most popular, with an impressive number of readers and online contributions. There is also a notable difference regarding the extent to which online and offline practices are integrated in the U.S. and France. In contrast to French contributors, most American online contributors rarely use blogs and fora to organize offline events or to inform readers about them. Furthermore, on French online platforms, exchanges unfold among people diagnosed with comparable levels of authority and influence. In the U.S., however, some individuals diagnosed with bipolar disorder have become highly influential, thereby shaping how other people diagnosed and their families understand and approach this condition. More studies are needed to acquire a better understanding of the factors that account for such differences in the use of online platforms and their affordances among American and French online contributors, and of the standing the latter may come to occupy online.

6.1.4 The internet and its individualizing or collectivity-generating effects in relation to expertise

The findings of this study reveal that the internet has both individualizing as well as collectivity-generating effects in relation to expertise, as people diagnosed with bipolar disorder share their insights on this condition online. The analysis in chapter 3 shows that the internet can contribute to the development of new individual-group configurations. The online contributors studied share their treatment experiences as individuals rather than representatives of certain groups, and their interactions with others are most of the time too fleeting for actual communities to develop. Nevertheless 'light' forms of collectives do come into being. Such collectives do not develop, however, through the agency of the online contributors alone, but rather as an effect of the online affordances of blogs and fora, which group together online contributors based on the posts and threads they react to and which allow for the accumulation of their insights in the same spaces. Furthermore, the readers of these platforms may also group these contributions into different sets of (sub)groups, based on commonalities or differences in the effects and side-effects of specific medications or based on other criteria they find significant. Importantly, even though online contributors can decide never to return to a specific online platform again, unless they delete their contribution, they continue to be part of that collective long after their last visit, through the insights they have shared. Certain online affordances available on these platforms may further serve as reminders of their participation, as notifications about new comments or about specific reactions to their own contributions may allow people diagnosed to keep track of reactions on that platform, even when they no longer participate actively.

Closely-knit collectivities can also develop online, as chapter 5 has shown. I have termed such (sub)groups "digital biocommunities" to highlight the fact that they are not only brought together by increasingly more specific commonalities of experience, but also by shared approaches to the technologies of fora. Thus, online contributors are drawn together by similar interests, as they react to specific forum threads, by common attitudes about their condition and the social-political circumstances they are living in, which they can refer to in brief or more elaborate forms through the use of specific online affordances available on these platforms. The analysis thus shows that the internet facilitates in such circumstances the coming together of people diagnosed with bipolar disorder into new types of (sub)groups. This happens as the online affordances available on interactive platforms enable them to acquire intimate knowledge of each other, to provide support and encouragement.

In contrast, chapter 4 reveals that the use of the internet contributes to the development of a new type of individual stakeholder, what I have called "online expert mediators". This new stakeholder category emerges at the intersection between the diagnosis of bipolar disorder, the acquisition of particular types of knowledge and an individual's skillful use of the internet. It has also been made possible by the limited trust some of the people diagnosed and their families have towards medical professionals due to various scandals over the last two decades regarding the close ties between psychiatrists and pharmaceutical companies. The rise of online expert mediators may mark a turn from community activism to exceptional entrepreneurial selves. Thus, Tracy and Fast have managed to turn their diagnosis into a source of livelihood by engaging in numerous actions as individuals, by using personal assets and skills, rather than as members of patient organizations, who could thus gain access to the resources of the entire organization and benefit from the support of its other members. This study has therefore identified a new form of individualization as well as a new form of collectivization that the internet contributes to, and has shown that both forms exist simultaneously online.

By using the concept of interactional expertise to study the activities of these online expert mediators, expertise about bipolar disorder was approached as the property of individuals. In so doing, however, the role of medical professionals and other people from whom these bloggers learned before starting their own blog, the influence and input of legal experts, assistants, and other professionals they most likely employed, the inspiration and new insights they acquired from the contributors on their platforms were not taken into account. This was partly due to limited access to these bloggers, as only Fast agreed to answer a few questions via an e-mail interview, and partly because of the careful way in which they curate their public personas and the information available about them. While it may well be that Fast is right and that readers “appreciate quality above all else” (e-mail interview, 2017), more studies on the behavior of different online audiences and their online preferences are needed, in order to understand what such popularity is based on. It is also important to acquire more information about the demographics and specific needs of their audiences, since these bloggers have also been working as personal coaches and have been providing guidance and advice to individuals diagnosed with various mental conditions. Given that socio-economic inequalities have been shown to influence the quality of (professional) care one receives when healthcare is provided through public-private partnerships (Engel & Van Lente, 2014), it is necessary to understand whether online expert mediators represent a cheap(er) way to access medical information for people with limited resources or an additional means through which those sufficiently well-off may seek to manage their health. Furthermore, more insights are needed into the ways in which such highly influential individuals diagnosed with mental health conditions collaborate with medical institutions and how the terms and conditions of their collaborations are negotiated.

As the online contributions studied here come from online platforms with free access, the internet could also contribute to harming the people who provided these insights in more direct ways, if the platform owners sell such data to employers, insurance companies, banks and other institutions that importantly shape one’s quality of life. Further studies are also needed on the role of platform owners in the online sharing and production of knowledge. It would also be important to understand how they decide on the online affordances available on their platforms, and whether the changes they make in this sense are the result of breakdowns, quick fixes, imitation or careful consideration and strategy.

6.2 Knowledge production in the digital age – contributions

In this section, I discuss the significance of the findings described above by considering their relevance in regard to processes of knowledge production in the digital age and to the role the internet plays in them. In so doing, I argue that we need to move beyond rather simplistic approaches which see the internet either as a quick technological fix or a postmodern version of Pandora’s box.

6.2.1 Expertise and typically human competencies

The findings presented in this dissertation are the result of a qualitative study, which has focused on the narrative accounts provided by various stakeholders on different types of online platforms. Yet, this research has unfolded against a background where developments in digital technologies and data analytics have led many to believe that the days of the relevance of human knowledge as we know it are counted. Enthusiastic about the capacities and potential of high-performing intelligent machines, such commentators — often developers or owners of digital companies— believe the acquisition of huge amounts of data from numerous individuals (will) enable computers and algorithms to provide better, more relevant solutions to all sorts of problems (Mayer-Schönberger & Cukier, 2013). Such processes are underlined by a shift from causation to correlation in the development of knowledge, as such technologies can process at great speed previously unimaginable volumes of data, and identify relevant patterns. The insights thus acquired are appealing to many, especially to those who find themselves at sufficient distance from these technologies, not only because of the remarkable calculations upon which they are based, but also because of their apparent objectivity, as human bias is (mistakenly) thought to be largely removed from them. Importantly, such digital technologies are thought to already constitute or promise to become better alternatives to human expertise and the many flaws that are imputed to it due to insufficient or fragmented access to information, limited capacities to process all relevant data and to make accurate predictions in regard to complex phenomena, and personal or collective ideologies and interests (Topol, 2019). In this context, knowledge produced by digital technologies and algorithms is made to shine brighter, due to its perceived neutrality and objectivity.

This study tells, however, a different story, as it emphasizes the importance of several typically human competencies, such as sensitivity to context, norms and values, for the enactment of expertise. By studying how governmental agencies and people diagnosed with bipolar disorder enact expertise online, I argue that expertise could better be approached as a practical achievement, realized through coordination and affective labor among stakeholders with different types of knowledge, who occupy multiple, shifting positions across a complex ecosystem. One of the merits of this conceptualization is that it focuses on affective labor, showing that it plays an important role in epistemic practices. This is particularly important in the current context, where big data enthusiasts have started to invoke affective practices to argue in favor of using artificial intelligence (AI) in medical practice. Thus, Topol (2019) claims that the use of AI as diagnostic tools would free up time for medical professionals to be more "present", "humane" and "empathetic" during their encounters with patients. Furthermore, he argues that "it is essential that we upgrade diagnosis from an art to a digital-driven science" (Topol, 2019: Loc. 893). As this last statement shows, such visions do not consider affective labor and practices as part of (medical) expertise, of epistemic practices, but rather as something different, that can be separated from the former, and that can be called upon and managed.

The findings presented in this dissertation have shown, however, that affective labor is closely tied to the development and enactment of expertise, and that this relation is not limited to people diagnosed (chapter 5), but is also mobilized in the development and translation of knowledge among different communities of practice (chapter 4). Thus, affective practices, creativity, and adaptability are typically human capabilities that have been shown to play a significant role in the production of knowledge, as well as in its accurate interpretation and successful implementation. This is in line with arguments developed by Collins (2018) in his study on artificial intelligence, where he highlights the importance of context-sensitivity and language acquisition in regard to expertise. In his opinion, such abilities can only be acquired through acculturation in a given society and are importantly tied, from a collective point of view, to embodiment, to the ways in which one makes sense of the world with and through one's body. Furthermore, Collins emphasizes that in their interactions with others, people constantly engage in substantial, highly complex forms of "repair work", as they make sense of, adapt, fill in, and modify the broken and incomplete information they receive, in order to develop appropriate responses. The findings presented in chapter 3 of this dissertation confirm this perspective, because they highlight the adaptative character of expertise, as general views on the effectiveness of medications or on the manifestations of bipolar disorder are enriched by being assessed and applied to the specific circumstances, needs and preferences of various individuals. That epistemic practices are also affective in various ways is important not only from a scientific point of view, but also politically, especially given the skewed gendered distribution and income inequality characterizing professions where care rather than knowledge are highlighted (Hochschild, 1983/2003).

Another problematic aspect is that affective labor is framed by big data enthusiasts as something that occurs without the mediation of technology, when doctors can take their eyes away from computers and scans, and look instead at the patient. The findings presented here have shown, however, that digital technologies are an integral part of certain affective practices, shaping how people perform affective labor, and who the performers and recipients of affective labor can be. Studying affective labor online is important also because of the growing amount of value that is nowadays generated from the cognition, communication, affect, and the immaterial actions of online "prosumers" (Berardi, 2009; Hardt & Negri, 2004) and because scholars are divided about the role of such labor in digital media economics. Thus, many have criticized users' engagement with digital technologies as a form of free labor (Lupton, 2014; Mitchell & Waldby, 2010; Waldby & Cooper, 2008; Terranova, 2000), particularly since people are typically required to give up ownership over their data and any claims over potential profits that can be made from them. The findings presented in this dissertation provide, however, a more nuanced perspective, as they show that online contributors perform affective labor in order to assist others, but they also benefit in various ways from these efforts, either because such practices contribute to their wellbeing or because they receive similar assistance from others, when they need it.

This dissertation has also shown that norms and values play an important role in the enactment of expertise, not as sources of bias that need to be overcome, but as factors that motivate people to contribute in specific ways to knowledge production. Thus, chapter 3 has highlighted the role personal values and preferences play in how people assess treatment effectiveness and the therapeutic improvements or new treatments that they seek to contribute to, by sharing their personal experiences and insights. Whereas currently dominant neoliberal imperatives encourage individuals to assume responsibility for their health, chapter 5 has shown that lay expertise is importantly tied to the value of solidarity. Thus, people diagnosed with bipolar disorder individually enact lay expertise and/or contribute to its collective development, as they are motivated to share the insights they have acquired, because of important similarities between themselves and others. From this point of view, this dissertation contributes to the work of several philosophers of expertise (Goldman, 2018; Quast, 2018), who have highlighted the moral dimension of expertise. These authors have argued that people endowed with expertise are expected to behave responsibly, reflexively and virtuously, and to assist others to the best of their abilities. While solidarity is largely neglected from such considerations, the findings presented in chapter 5 suggest that it is a value that is worth paying more attention to in relation to expertise. Furthermore, by revealing the importance of affective labor for epistemic practices, this dissertation also expands the category of behaviors people endowed with expertise engage in and need to be aware of.

The findings of this study which highlight the importance of communities for knowledge production are also important, as we currently "live in an environment in which datafied individualization of health responsibility appears like an inevitability" (McFall, 2019: 61). From this point of view, the internet could be seen to finally live up to some of the visions it generated in its early days, when many expected it to lead to the development of virtual communities, as people with the same diagnosis could thus easily come together and talk about matters of interest, regardless of where they lived (Eysenbach, 2005; Hardey, 1999). The findings presented in chapter 5 have confirmed, but also nuanced these expectations, as they have revealed that people diagnosed with bipolar disorder develop digital biocommunities based on increasingly more specific commonalities. This study has thus contributed to a growing body of literature (McFall, 2019; Prainsack & Buyx, 2018; Sharon, 2017; Van Hoyweghen & Rebert, 2012) that seeks to highlight the importance of solidarity for the ways in which people diagnosed relate to their condition. It has shown that through extensive online interactions, people could engage in practices which were beneficial for themselves as well as for others, and they could lay claim, even for brief exchanges, to other identities than that of vulnerable, sick people. By sharing their insights, by describing the strategies they developed to improve their daily lives with bipolar disorder, they could take the role of counselors or advisors for other people diagnosed who were going through a hard time and, in so doing, they contributed to the collective development of lay expertise.

The conceptualization of expertise that I put forward also highlights the complexity and diversity which characterize the production of knowledge in the digital age and the dynamic ways in which authority and influence can be (re)distributed among relevant stakeholders. This is important, because in many situations a priori agreements about the identity of the "experts" or of the stakeholders involved in the development of expertise no longer hold, the relevance and impact of their input differs depending on the problem they are called to solve, and their role may change as new tools or practices are introduced (Waardenburg el al, 2018). From this point of view, the findings presented here constitute a contribution to the growing body of expertise studies, which emphasize the fact that nowadays individuals or groups socialized within different epistemic cultures have to intensely negotiate the relevance of their insights and the reach of their influence (Holst & Molander, 2018). By focusing on the knowledge with which different stakeholders are endowed, the new approach I put forward also highlights the importance of combining not only different types of theoretical knowledge, but of bringing together scientific insights with relevant local factors that only specific stakeholders may have knowledge of. This new conceptualization of expertise is thus in line with arguments recently provided by Barrotta and Montuschi (2018: 395), who state that "local knowledge coming from 'other sources' is often necessary to fill the gap between experts' knowledge and correct judgement calls." Another merit of this approach to expertise it that it draws attention to the importance of the ecosystem within which relevant stakeholders are based, as even sound recommendations may be thwarted or lead to less desirable effects depending on the available infrastructures, policies, legal provisions, and dominant political climate.

This study is therefore a contribution to the work of STS scholars who have cautioned against the hype surrounding digital technologies and their epistemic potential (Neff, 2013) and have argued, instead, that certain typically human capabilities continue to be very much needed in processes of knowledge production. These findings are thus important reminders of the value of nuanced perspectives, developed through rich, detailed studies, for a better understanding of the different functions and roles that people and digital technologies fulfill in processes of knowledge production. Whereas considering the online knowledge thus generated as mainly the merit of the technologies used would be a serious mistake, neglecting the active ways in which the latter do shape the content produced would be a danger that STS scholars have repeatedly warned against (Swierstra, 2016; Wyatt et al, 2016).

6.2.2 The role of the internet in processes of knowledge production

Despite tendencies to frame discussions on the role of the internet in healthcare in technical terms, its use often leads to problems of a social and cultural nature, which require non-technical solutions. In this dissertation, I have shown that the use of the internet to enact expertise about bipolar disorder is not merely a question of the availability of certain online platforms, nor are the capacities required to use them evenly spread. The findings presented here have indicated, instead, that through such interactions, people's understanding, behaviors and values can be transformed, as technologies are not neutral, nor passive, but "nudge", seduce or entice people in certain directions. They thus enable them to enact certain values rather than others or to take up and propagate certain visions of good patienthood rather than others.

The internet has played an important role in assisting people diagnosed with bipolar disorder move beyond the enactment of lay expertise and engage more closely in the production of knowledge through the development of hypotheses about treatment effectiveness. In his recent study on medical expertise, Engeström (2018:42) advocated for people diagnosed and medical professionals to "try and create instruments with which they can take advantage of their differences", but remarked that "[t]his requires new mediating artifacts". This dissertation has shown instead that blogs and fora can constitute such mediating artifacts between people diagnosed with bipolar disorder with different symptoms, treatment experiences, and social life circumstances.

Another important contribution this dissertation makes is the identification of the development of a new stakeholder category, what I have termed "online expert mediators", who engage in substantial collaborations with medical professionals as well as people diagnosed with bipolar disorder as a result of their online activities. The field of bipolar disorder has been influenced by insights acquired from medical professionals diagnosed with this condition, such as Professor Kay Redfield Jamison,[17] whose work and perspectives have exerted a great influence on the ways in medical professionals, people diagnosed and carers seek to manage this condition. The position occupied by the two online expert mediators studied in this dissertation remains, however, unprecedented in the field of mental health for individuals diagnosed with bipolar disorder and lacking

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[17] For instance, together with psychiatrist Frederick Goodwin, in 1990 she published the book *Manic Depressive Illness. Bipolar Disorder and Recurring Depression***,** which has since become a 'classic text' in the field and has been published in two editions.

official accreditations, as they actively engage in the production of scientific knowledge and shape the ways in which this condition is understood by a broad public. I have argued that this new stakeholder category represents a very specific and particularly successful form of entrepreneurial selves, which has become possible in a context where expectations about the role of (potential) patients have changed from passive recipients of care to informed citizens and active managers of their health. In so doing, this study contributes to medical sociology and the branch of media studies focusing on the ways in which digital technologies shape people's health behaviors. Particularly relevant in this sense has been the study conducted by Versteeg and colleagues (2018:447), who have suggested that "[i]t seems more fruitful to take into account the identities that people build for themselves" in this new context, and who argued for the necessity to understand people's inquisitive and critical behavior as the result of visions of good patienthood that are currently propagated.

There is little doubt that the internet played a crucial role in the development of this new stakeholder category, not only because it provided these bloggers with quick and relatively affordable access to the public sphere, but also because of the various ways in which it facilitated their rise to prominence. The high standing achieved by these bloggers is partly due to the fact that they have been among the first to realize both the potential of such online technologies and the need among people diagnosed with bipolar disorder to acquire insights made available by other people diagnosed. The authority of their insights is to a large extent due to their high number of readers and/or online contributors on their platforms. The Matthew effect as well as the important ties they developed with relevant institutions and medical professionals might have been at play here, as a high number of readers is not only seen as an indicator of popularity, but also of legitimacy online. It may thus have prompted more people in search of reliable information about bipolar disorder to consult these blogs. Furthermore, the algorithms of search engines have also played an important role in raising the visibility of these two bloggers, as the platforms where they contribute are mentioned multiple times on the first page of results, either directly or on lists of the best bipolar blogs. While a lot remains to be known about the elements that are included in these algorithms and about the individual weight which they are ascribed, a skillful use of the information currently available about these matters can importantly influence the traffic on a platform (Noble, 2018). This is the case because people in search of information are more likely to access the links provided on the first result pages and not move beyond them, if they are satisfied with the information encountered there.

Even though many people initially believed that the use of the internet in mental healthcare would lead to a re-appreciation of the experiential knowledge of people diagnosed (Hardey, 1999), the findings presented in this dissertation suggest that this medium can lead to the development of new epistemic asymmetries (Holst & Molander, 2018). For instance, important differences can be noted between the standing, authority, and influence of online expert mediators compared to the individuals diagnosed with bipolar disorder described in chapters 3 and 5. This is important given the charge of being undemocratic, currently brought against the use of expert opinion for policy decisions. Thus, many have argued that it is not enough to make competing expert claims or recommendations available to the public in order to ensure that they can make well-informed decisions or that their political rights and liberties as citizens living under democratic regimes are respected. According to Holst and Molander (2018), an important condition that is often not met is to ensure that people can actually understand what are often very technical and complex competing scientific claims. From this point of view, rather than an example of new epistemic asymmetries, online expert mediators may contribute to more democratic relations between experts and the public, as they may help the latter make better sense of the insights provided by scientists and thus become better informed.

The findings presented in this dissertation contribute to media studies, public health policy and interface design, as they indicate that cultural elements not only shape the content of online interactions between people diagnosed with bipolar disorder, but also their attitudes and preferences for specific online technologies. For instance, the French fora studied here had a much more interactive character than blogs, whereas in the U.S. the situation was reversed. Being aware of such differences is important at a time when international, concerted actions are organized to address conditions with high prevalence of disability worldwide, as it highlights that even online policies and strategies need to be adapted to local contexts. Other findings in this dissertation showed that important differences may exist among online users from the same country based on religious affiliation, type of employment, personality. This means that official institutions that seek to use the internet to provide more cost-effective mental healthcare and to reach more people in need have to take into account the heterogeneity of the population they address across more markers.

This dissertation has shown that different stakeholders enact expertise about bipolar disorder in different ways, depending on their skills and resources, on the ways in which they (can) choose to react to broader social transformations, and on the values that underlie their engagements. The ways in which science and knowledge production are currently structured and organized increasingly require experts to make bold claims and to issue clear, unwavering recommendations about the problems they are called to solve. The varied and numerous accounts, doubts, and uncertainties expressed by the people diagnosed with bipolar disorder studied here constitute important reminders, however, that modesty, diversity of opinions, and constructive criticism are essential elements in the development of sound knowledge. By cultivating and enhancing the internet's potential towards inclusive participation and (self)reflection, inquiries about the meaning and relevance of expertise will continue to generate enthusiasm, excitement, and heated debates. Many more exhilarating questions are thankfully opening up…

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Appendix A

Description of selected platforms

APPENDIX A.

DESCRIPTION OF SELECTED PLATFORMS

National Institute of Mental Health

The National Institute of Mental Health (NIMH) is the main agency of the American government responsible for biomedical and health-related research. It is the largest research organization in the world focusing on mental health. With a budget of about $ 1.5 billion, NIMH conducts its own research, but largely determines the national research agenda by providing grants to other institutes and organizations throughout the U. S. NIMH appear to position themselves as a first point of entry for people interested in bipolar disorder, as they provide accepted, yet rather generic information, and use terms which can be easily understood by most readers.

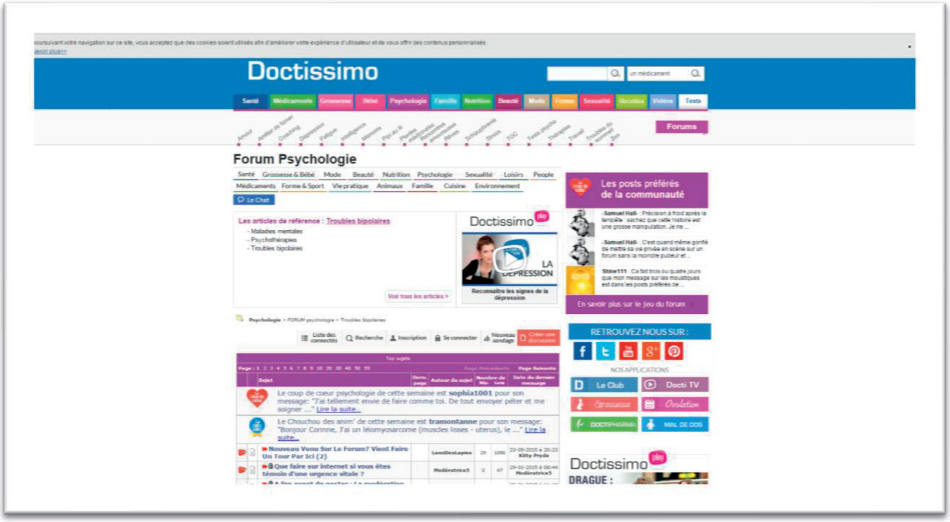
La Haute Autorité de Santé

The Haute Autorité de Santé (HAS) is an independent public institution with a scientific character, created in 2004. Interestingly, its board consists of eight members appointed for six years (with the possibility of renewal every three years) by the President of France (two members can be proposed by the President himself, two by the President of the Senate, two by the President of the National Assembly, and two by the President of the Economic, Social, and Environmental Council (CESE). HAS fulfills three main functions: (1) to evaluate from a medical and economic point of view health products, technologies, and practices in view of their admission for reimbursement (a French version of Health Technology Assessment); (2) to provide recommendations on healthcare practices, public health; to create guide books on treatment both for patients and medical professionals; to develop medico-economic studies; to advise public institutions in their decisions regarding public health; and to define the trajectory of personalized care to which one is entitled; (3) to certify healthcare establishments and to provide accreditations for medical professionals. Very important for this project is that HAS also certifies health-related online platforms. Its current annual budget is € 60 million, and its revenues come from taxes on promotional spending by drug companies, from National Health Insurance, state funding, HCO accreditation fees, payment for assessing applications for inclusion on reimbursement lists, etc.

Doctissimo

Doctissimo is a commercial platform dedicated to various health issues, which was founded in 2000, and is the property of the Lagardère Group since 2008. It is one of the most popular sites on health-related issues in France, with more than eight million visitors per month. Somewhat similar to NAMI, it has also been surrounded by scandal, with accusations that popular online search entries are used by the Lagardère group in order to determine the type of information to be published in their numerous newspapers and magazines. Moreover, Doctissimo has also failed to obtain the HonCode and the HAS certifications which acknowledges that the information they provide is authoritative. Next to medical information, Doctissimo also contains a few lifestyle rubrics (Figure A.A.1). This information suggests that this platform is a real battleground of expertise on treatment.

Figure A.A.1 Screenshot of the main webpage about bipolar disorder on *Doctissimo*. Retrieved on June 14, 2015.



-Samuel Hall- : Précision à froid après la tempête : sachez que cette histoire est une grosse manipulation. Je ne ...

-Samuel Hall- : C'est quand même gonflé de mettre sa vie privée en scène sur un forum sans la moindre pudeur et ...

Shine111 : Ca fait trois ou quatre jours que mon message sur les moustiques est dans les posts préférés de ...

Le coup de coeur psychologie de cette semaine est **sophia1001** pour son message: "J'ai tellement envie de faire comme toi. De tout envoyer péter et me soigner ...." Lire la suite...

Le Chouchou des anim' de cette semaine est **tramontanne** pour son message: "Bonjour Corinne, J'ai un léiomyosarcome (muscles lisses - uterus), le ...." Lire la suite...

Nouveau Venu Sur Le Forum? Vient Faire Un Tour Par Ici (2)

Que faire sur internet si vous êtes témoin d'une urgence vitale ?

Doctissimo also sells advertising space, and can be "hired" to focus on specific topics. Since June 2013, under French law, people can order online medicines without prescription, so Doctissimo launched the DoctiPharma site in 2014 for such purposes (Figure A.A.2).

Figure A.A.2 Screenshot of the online pharmacy site on *Doctissimo*. Retrieved on June 14, 2015.

En poursuivant votre navigation sur ce site, vous acceptez que des cookies soient utilisés afin d'améliorer votre expérience d'utilisateur.

En savoir plus>>

The platform of Doctissimo consists of numerous articles and entries regarding the symptoms and forms of treatment available for various conditions, but also hosts numerous forums (Figure A.A.3), provides relevant videos, and even includes micro documentaries. It is therefore a combination of an inter-active and non-interactive site, and has a deep structure, as readers can click on the multiple hyperlinks provided on each page. The design of the site is colorful, containing numerous images. The forum discussions are monitored, and under French law, the owners have an obligation to inform the authorities in case the statements made by contributors lead them to believe they may represent a danger to themselves or others.

Figure A.A.3 Screenshot of a forum on bipolar disorder on Doctissimo. Retrieved on November 3, 2015.

-Samuel Hall- Précision à froid après la tempête : sachez que cette histoire est une grosse manipulation. Je ne ...

-Samuel Hall- C'est quand même gonflé de mettre sa vie privée en scène sur un forum sans la moindre pudeur et ...

Shine111 Ca fait trois ou quatre jours que mon message sur les moustiques est dans les posts préférés de ...

Posté le 14-07-2015 à 03:03:55

Bonjour,

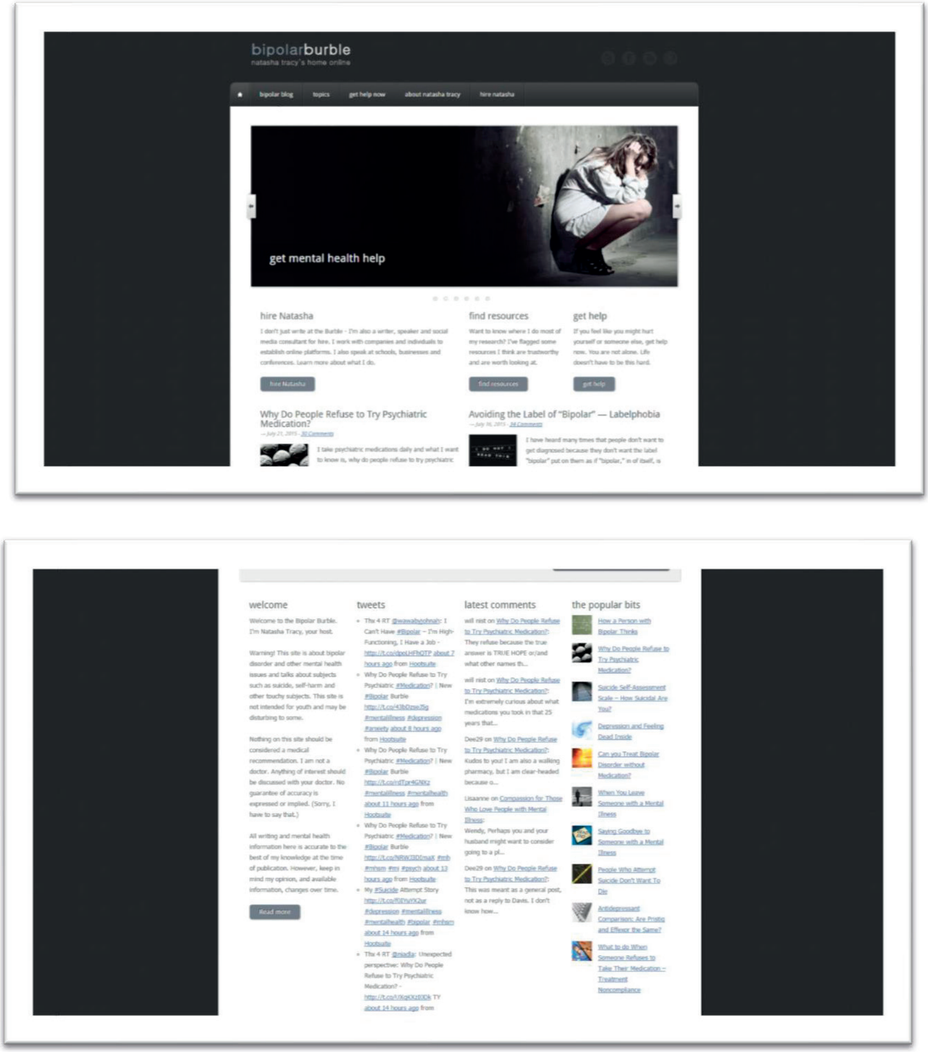
Je suis souvent fatigué sans raison même après une bonne nuit de sommeil (je dors longtemps d'ailleurs), sensation de ne pas avoir d'énergie en général, d'être au ralenti. Sensation de dépit au réveil ou quand je vais dormir. J'ai des changements d'humeurs au cours de la journée (normal, triste, joyeux, énervé...) même si j'ai tendance à être plus triste/nostalgique du passé. Parfois je ne supporte rien et je m'énerve pour pas grand chose, j'ai besoin de rester seul assez souvent. Je peux être d'humeur normale voire positive et baisser complètement les bras, voir tout en noir en peu de temps. Beaucoup de mal à me concentrer dans mon travail (je travail chez moi sur internet) et à respecter des horaires, je manque de sérieux mais c'est plus fort que moi. Je suis peu motivé pour sortir en général, ça me fatigue, je prends peu d'initiatives et j'ai tendance à rester dans mon coin. Tout ça fait que ça gâche ma relation avec ma copine qui ne supporte plus de me voir comme ça, je suis conscient que je ne suis pas facile à vivre mais je ne sais pas comment résoudre mes problèmes.

J'ai l'impression de n'avoir le temps de rien faire, je suis souvent triste. Un peu comme si chaque jour est une corvée, une épreuve, c'est très démoralisant à la longue. Et ça ne change pas. J'ai aussi des TOC.

Bipolar Burble

This is the personal blog of Natasha Tracy, diagnosed with bipolar disorder, who has been writing about bipolar disorder for a long time and on different platforms. She was the author of "Bipolar" on the lifestyle platform **Answers**, and of "Bipolar Bites" at **Healthline**. Having a celebrity status among people with or interested in bipolar disorder, Tracy can also be hired to give talks and to attend various events. Thus, the blog also functions as a form of personal advertisement of her professional activities and competences (Figure. A.A.4).

Figure A.A.4 Screenshot of the main page on *Bipolar Burble*. Retrieved on July 23, 2015.



hire Natasha

I don't just write at the Burble - I'm also a writer, speaker and social media consultant for hire. I work with companies and individuals to establish online platforms. I also speak at schools, businesses and conferences. Learn more about what I do.

find resources

Want to know where I do most of my research? I've flagged some resources I think are trustworthy and are worth looking at.

get help

If you feel like you might hurt yourself or someone else, get help now. You are not alone. Life doesn't have to be this hard.

Why Do People Refuse to Try Psychiatric Medication?

— July 21, 2015 - 30 Comments

I take psychiatric medications daily and what I want to know is, why do people refuse to try psychiatric

Avoiding the Label of "Bipolar" — Labelphobia

— July 16, 2015 - 34 Comments

I have heard many times that people don't want to get diagnosed because they don't want the label "bipolar" put on them as if "bipolar," in of itself, is

welcome

Welcome to the Bipolar Burble. I'm Natasha Tracy, your host.

Warning! This site is about bipolar disorder and other mental health issues and talks about subjects such as suicide, self-harm and other touchy subjects. This site is not intended for youth and may be disturbing to some.

Nothing on this site should be considered a medical recommendation. I am not a doctor. Anything of interest should be discussed with your doctor. No guarantee of accuracy is expressed or implied. (Sorry, I have to say that.)

All writing and mental health information here is accurate to the best of my knowledge at the time of publication. However, keep in mind my opinion, and available information, changes over time.

tweets

- Thx 4 RT @wawabyjohnah: I Can't Have #Bipolar – I'm High-Functioning, I Have a Job - http://t.co/dpoLHFhOTP about 7 hours ago from Hootsuite
- Why Do People Refuse to Try Psychiatric #Medication? | New #Bipolar Burble http://t.co/43bOzseJ5g #mentalillness #depression #anxiety about 8 hours ago from Hootsuite
- Why Do People Refuse to Try Psychiatric #Medication? | New #Bipolar Burble http://t.co/rdTpr4GNKz #mentalillness #mentalhealth about 11 hours ago from Hootsuite
- Why Do People Refuse to Try Psychiatric #Medication? | New #Bipolar Burble http://t.co/NRW3lDImaX #mh #mhsm #mi #psych about 13 hours ago from Hootsuite
- My #Suicide Attempt Story http://t.co/f0IYuYX2ur #depression #mentalillness #mentalhealth #bipolar #mhsm about 14 hours ago from Hootsuite
- Thx 4 RT @niadla: Unexpected perspective: Why Do People Refuse to Try Psychiatric Medication? - http://t.co/UXgKKzI0Dk TY about 14 hours ago from

latest comments

will nist on Why Do People Refuse to Try Psychiatric Medication?: They refuse because the true answer is TRUE HOPE or/and what other names th...

will nist on Why Do People Refuse to Try Psychiatric Medication?: I'm extremely curious about what medications you took in that 25 years that...

Dee29 on Why Do People Refuse to Try Psychiatric Medication?: Kudos to you! I am also a walking pharmacy, but I am clear-headed because o...

Lisaanne on Compassion for Those Who Love People with Mental Illness: Wendy, Perhaps you and your husband might want to consider going to a pl...

Dee29 on Why Do People Refuse to Try Psychiatric Medication?: This was meant as a general post, not as a reply to Davis. I don't know how...

the popular bits

- How a Person with Bipolar Thinks
- Why Do People Refuse to Try Psychiatric Medication?
- Suicide Self-Assessment Scale – How Suicidal Are You?
- Depression and Feeling Dead Inside
- Can you Treat Bipolar Disorder without Medication?
- When You Leave Someone with a Mental Illness
- Saying Goodbye to Someone with a Mental Illness
- People Who Attempt Suicide Don't Want To Die
- Antidepressant Comparison: Are Pristiq and Effexor the Same?
- What to do When Someone Refuses to Take Their Medication – Treatment Noncompliance

Her blog is extremely popular, with comments to certain blog entries attracting typically hundreds of reactions from various stakeholders (Figure A.A.5), including medical professionals, people diagnosed, care givers, or curious readers. Even though the blog belongs to an individual, and it does not appear to be subject to limitations from another party, no space has been made available for advertisements (Figure A.A.5).

Figure A.A.5 **Screenshot with the number of comments to an entry on *Bipolar Burble*. Retrieved on July 23, 2015.**

And this is beyond difficult. Trying to defeat the way a bipolar brain thinks is near-on impossible. Dealing with bipolar thoughts is a full-time gig and an exhausting one at that. But it is important. Because if we don't moderate our own thoughts and deal with them appropriately, we can't hope to have healthy relationships with others. And if that happens then all those pesky catastrophes we worried needlessly about will have come true.

Related

Bipolar Disorder and Obsessive Thoughts
In "Bipolar blog"

Getting Your Doctor to Take Your Bipolar Seriously if you're High-Functioning
In "Bipolar blog"

Coping with Bipolar Emotions Using Logic
In "Bipolar blog"

ADHD, anxiety, bipolar thinks, bipolar thought, catastrophizing, obsession, obsessive thoughts, OCD

I write a three-time Web Health Award winning column for HealthyPlace called Breaking Bipolar.

The Bipolar Bites archive.

the archives

the archives

Select Month

525 Comments

Join the conversation → Add yours

Ashok Kumar - July 22, 2015
I first felt hypomanic when I was 18 year old.I had just passed my 12th standard in India and I had taken admission in a University for Bachelor of Science.My family had acute Financial problem and our survival was very difficult.I remain in that condition for almost three months and then I was normal.I did not know this as a disease so I did not seek any medicine.
It was a period when I was unusually very much enthusiastic.I had a lot of plans and very active with little sleep.I developed habit of writing short stories also and I was very much emotional.

Dez - July 19, 2015
Its nice reading this, thank you maybe im not alone or crazy. I feel im always apologizing.

Le Forum des Bipotes

Le Forum des Bipotes (LFB) is a forum for the “information, psychoeducation and mutual aid” of people diagnosed with bipolar disorder (Figure A.A.6). The forum was recommended on most of the other French non-interactive platforms examined, some of which were described above. Administrators are often chosen from among different medical professionals, and they actively monitor and react to people’s comments.

Figure A.A.6 Screenshot of the main webpage on *LFB*. Retrieved on July 23, 2015.

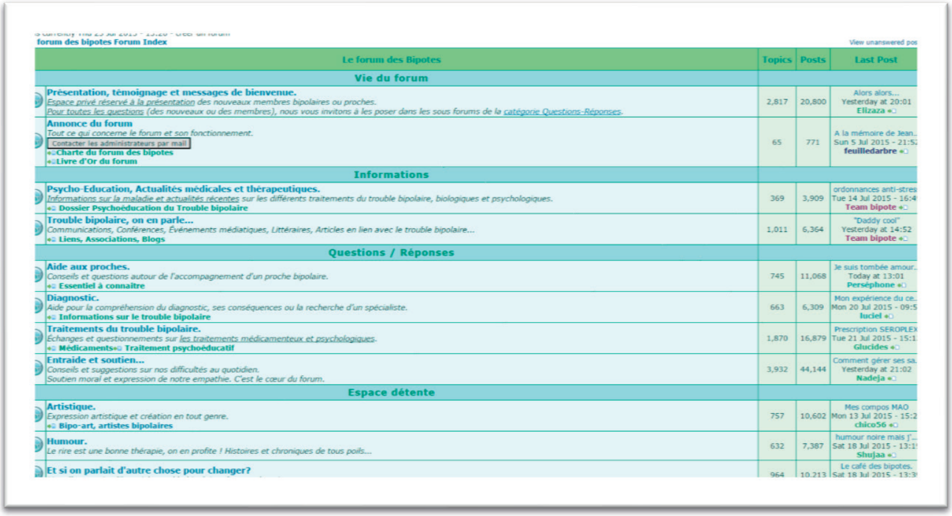
Forum d'information, de psychoéducation et d'entraide pour les personnes avec un trouble bipolaire (maniaco-dépression).

demain n'est pas encore là.

Prenez soin de vous et portez vous bien!

While any person can read the contents of the forum, those who wish to contribute need to register, and are subsequently invited by the administrator to introduce themselves on a section dedicated to new members. In order to do so they are required to provide information about their status in relation to bipolar disorder as well as about their location. The forum is further structured into four main sections: “Life of the Forum”; “Information”; “Questions/Answers”; “Relaxation Space” (Fig. A.A.7). Information is also provided about the members who are online at any given moment, and for each post, there are statistics available regarding the number of views and comments, the author of the post as well as the author of the last comment and the time when it was made. Also here, the comments are provided in chronological order.

Figure A.A.7 Screenshot of the structure and organization on *LFB*. Retrieved on July 23, 2015.



forum des bipotes Forum Index

View unanswered pos

Le forum des Bipotes	Topics	Posts	Last Post
Vie du forum			
Présentation, témoignage et messages de bienvenue. *Espace privé réservé à la présentation des nouveaux membres bipolaires ou proches.* *Pour toutes les questions (des nouveaux ou des membres), nous vous invitons à les poser dans les sous forums de la catégorie Questions-Réponses.*	2,817	20,800	Alors alors... Yesterday at 20:01 Elizaza
Annonce du forum *Tout ce qui concerne le forum et son fonctionnement.* Contacter les administrateurs par mail Charte du forum des bipotes Livre d'Or du forum	65	771	A la mémoire de Jean... Sun 5 Jul 2015 - 21:5 feuilledarbre
Informations			
Psycho-Education, Actualités médicales et thérapeutiques. *Informations sur la maladie et actualités récentes sur les différents traitements du trouble bipolaire, biologiques et psychologiques.* Dossier Psychoéducation du Trouble bipolaire	369	3,909	ordonnances anti-stres Tue 14 Jul 2015 - 16:4 Team bipote
Trouble bipolaire, on en parle... *Communications, Conférences, Événements médiatiques, Littéraires, Articles en lien avec le trouble bipolaire...* Liens, Associations, Blogs	1,011	6,364	"Daddy cool" Yesterday at 14:52 Team bipote
Questions / Réponses			
Aide aux proches. *Conseils et questions autour de l'accompagnement d'un proche bipolaire.* Essentiel à connaitre	745	11,068	Je suis tombée amour... Today at 13:01 Perséphone
Diagnostic. *Aide pour la compréhension du diagnostic, ses conséquences ou la recherche d'un spécialiste.* Informations sur le trouble bipolaire	663	6,309	Mon expérience du ce... Mon 20 Jul 2015 - 09:5 luciel
Traitements du trouble bipolaire. *Échanges et questionnements sur les traitements médicamenteux et psychologiques.* Médicaments Traitement psychoéducatif	1,870	16,879	Prescription SEROPLEX Tue 21 Jul 2015 - 15:1 Glucides
Entraide et soutien... *Conseils et suggestions sur nos difficultés au quotidien.* *Soutien moral et expression de notre empathie. C'est le cœur du forum.*	3,932	44,144	Comment gérer ses sa... Yesterday at 21:02 Nadeja
Espace détente			
Artistique. *Expression artistique et création en tout genre.* Bipo-art, artistes bipolaires	757	10,602	Mes compos MAO Mon 13 Jul 2015 - 15:2 chico56
Humour. *Le rire est une bonne thérapie, on en profite ! Histoires et chroniques de tous poils...*	632	7,387	humour noire mais j'... Sat 18 Jul 2015 - 13:1 Shujaa
Et si on parlait d'autre chose pour changer?	964	10,213	Le café des bipotes. Sat 18 Jul 2015 - 13:3

Sadly, after the founder and administrator of this forum passed away, the forum could no longer be maintained, despite the efforts undertaken by a team for a period of six months. The information has remained available, however, so that it could still benefit people, as Figure A.A.8 below indicates.

Figure A.A.8 Screenshot of the main page on LFB. Retrieved on September 14, 2018.

Bienvenue Guest

Parce qu'il ne trouvait pas ce qu'il souhaitait sur la toile, ***Bipote*** a créé ce forum en 2007 pour informer et venir en aide aux bipolaires et/ou aux proches. Il y a consacré beaucoup de temps et a espéré avoir répondu au mieux à ce besoin.

Malheureusement il nous a quitté en 2014 à la suite d'une longue et douloureuse maladie. Il a essayé jusqu'au bout de maintenir ce lieu convivial et très documenté.

Une nouvelle équipe a été créée pour continuer son oeuvre mais il fallait beaucoup de disponibilité et la charge est devenue beaucoup trop lourde pour la bénévole restante.

Son forum s'arrête donc là... et ses écrits, les écrits des proches et des bipotes comme il les appelait, sa documentation sont toujours disponibles ... peut être que vous y trouverez encore une réponse, une solution, une aide...

"Et n'oubliez pas, un bipolaire est avant tout une personne et tout n'est pas maladie"

Prenez soin de vous et portez vous bien !

** Toutes les informations ou avis sur le trouble bipolaire que vous pourrez lire ou recevoir sur ce forum ne doivent servir qu'à éclairer votre réflexion et à en discuter avec votre médecin. En aucun cas, cela ne saurait se substituer à une consultation médicale.*

Bipolar Happens!

Bipolar Happens! Is the personal blog of Julie A. Fast, person diagnosed with bipolar disorder and influential blogger about this condition and other mental health-related issues. Even though the number of interactions of this blog is fairly low, the blog is often voted among the best blogs on bipolar disorder, as you can see in Figure. A.A.9.

Figure A.A.9 Screenshots of the main page on the blog *Bipolar Happens!* Retrieved on November 30, 2018.

When a Partner with Bipolar Leaves the Home

Advice for when a partner leaves during an episode.

1. Know that this is normal. We flee we manic. We flee when the depression is too strong for us to stay in the same place. We flee when we can't manage our emotions. This doesn't make it ok or make it any less scary for you, but knowing that it's not ABOUT YOU is essential.

Here is more info on dysphoric mania- one of the main episodes that makes us flee:

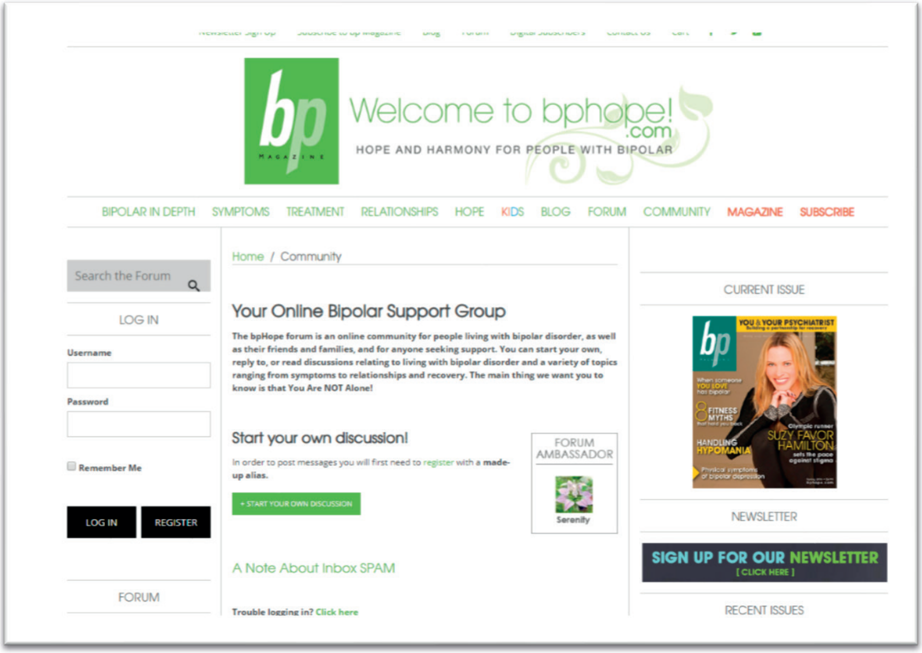
Dysphoric mania. I've got to get out of here! I hate my life!

Like Tracy, Julie A. Fast combines the provision of medical information with the sharing of strategies in order to better manage bipolar disorder on her blog. She also uses the blog to advertise her books and other services, as Figure A.A.9 indicates. She is also the author of a blog for *bp Magazine*.

Bp Hope Forum

This forum belongs to the bp Magazine, and was created in order to raise awareness about bipolar disorder and to allow different stakeholders, such as people diagnosed, carers, mental health professionals, to come together as peers and share their insights. The magazine is well-known among people with bipolar disorder, and its blog has received numerous awards. The forum's main focus on the provision of support is highlighted on the main page, where people are invited to contribute to ongoing discussions or to initiate one themselves, and they are reassuringly informed that "The main thing we want you to know is that YouAre NOT Alone!", as you can see in Figure A.A.10:

Figure A.A.10 Snapshot of the main image on the forum *Bp Hope*. Retrieved on July 16, 2016.



Your Online Bipolar Support Group

The bpHope forum is an online community for people living with bipolar disorder, as well as their friends and families, and for anyone seeking support. You can start your own, reply to, or read discussions relating to living with bipolar disorder and a variety of topics ranging from symptoms to relationships and recovery. The main thing we want you to know is that You Are NOT Alone!

Start your own discussion!

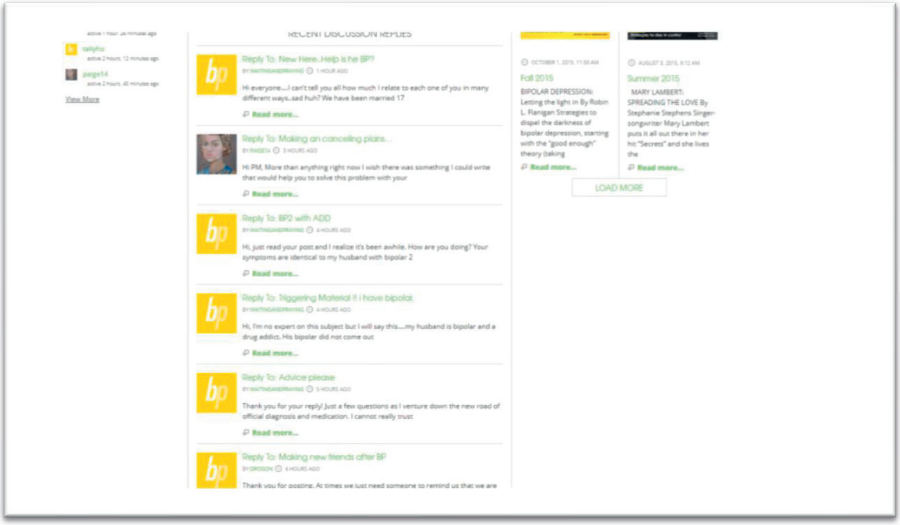
In order to post messages you will first need to register with a made-up alias.

A Note About Inbox SPAM

Trouble logging in? Click here

The main page of the forum is organized in a top-down fashion, with updates about the most recent discussions and about the most recent reactions provided beneath each other, as you can see in Figure A.A.10 above and Figure A.A.11 below.

Figure A.A.11 Snapshot of the lower part of the main page on the forum Bp Hope. Retrieved on July 16, 2016.



tallyho
active 2 hours, 12 minutes ago

paige14
active 2 hours, 45 minutes ago

View More

RECENT DISCUSSION REPLIES

Reply To: New Here..Help is he BP?
1 HOUR AGO
Hi everyone....I can't tell you all how much I relate to each one of you in many different ways..sad huh? We have been married 17
Read more...

Reply To: Making an canceling plans...
3 HOURS AGO
Hi PM, More than anything right now I wish there was something I could write that would help you to solve this problem with your
Read more...

Reply To: BP2 with ADD
4 HOURS AGO
Hi, just read your post and I realize it's been awhile. How are you doing? Your symptoms are identical to my husband with bipolar 2
Read more...

Reply To: Triggering Material !! i have bipolar.
4 HOURS AGO
Hi, I'm no expert on this subject but I will say this.....my husband is bipolar and a drug addict. His bipolar did not come out
Read more...

Reply To: Advice please
5 HOURS AGO
Thank you for your reply! Just a few questions as I venture down the new road of official diagnosis and medication. I cannot really trust
Read more...

Reply To: Making new friends after BP
6 HOURS AGO
Thank you for posting. At times we just need someone to remind us that we are

OCTOBER 1, 2015, 11:50 AM
Fall 2015
BIPOLAR DEPRESSION: Letting the light in By Robin L. Flanigan Strategies to dispel the darkness of bipolar depression, starting with the "good enough" theory (taking
Read more...

AUGUST 3, 2015, 9:12 AM
Summer 2015
MARY LAMBERT: SPREADING THE LOVE By Stephanie Stephens Singer-songwriter Mary Lambert puts it all out there in her hit "Secrets" and she lives the
Read more...

Appendix B

Overview of data selected for chapters 3 and 5

APPENDIX B.

OVERVIEW OF DATA SELECTED FOR CHAPTERS 3 AND 5

Table A.B.1: Overview of the online data used in the analysis of chapter 3

TITLE BLOG POST/ FORUM THREAD	NAME BLOG/ FORUM	NO. COMMENTS	THREAD
Why Take the Alternative Treatment EMPowerplus for Bipolar?	Bipolar Burble	60	http://natashatracy.com/treatment/alternative-treatment-empowerplus-bipolar/
I Know How To Cure Bipolar Disorder	Bipolar Burble	51	https://natashatracy.com/mental-illness-issues/cure-bipolar-disorder/
Under the Influence of Drugs- I Can Think Just Fine	Bipolar Burble	37	http://natashatracy.com/bipolar-disorder/under-influence-drugs-can-think-fine/
Antidepressants and Addiction, Dependence-Talkback	Bipolar Burble	42	https://natashatracy.com/mental-illness-issues/antidepressants-addiction-dependence-talkback/
A Bipolar Life Without Medication- A Possibility?	Bipolar Burble	104	https://natashatracy.com/bipolar-disorder/bipolar-life-without-medication/
Bipolar Treatment Fatigue	Bipolar Burble	48	https://natashatracy.com/bipolar-disorder/bipolar-treatment-fatigue/
What You Should Eat When Taking Geodon-Food and Geodon	Bipolar Burble	41	https://natashatracy.com/treatment-issues/side-effects/eat-geodon-food/
How To Get Off Antidepressants Effexor/Pristiq (Venlafaxine/Desvenlafaxine)	Bipolar Burble	92	https://natashatracy.com/treatment-issues/withdrawal/antidepressants-effexorpristiq-venlafaxinedesvenlafaxine/
Why Do People Refuse To Try Psychiatric Medication?	Bipolar Burble	125	http://natashatracy.com/treatment-issues/people-refuse-psychiatric-medication/
Can You Treat Bipolar Disorder Without Medication?	Bipolar Burble	246	http://natashatracy.com/bipolar-disorder/treat-bipolar-disorder-medication/

Continued

Table A.B.1: Overview of the online data used in the analysis of chapter 3

TITLE BLOG POST/ FORUM THREAD	NAME BLOG/ FORUM	NO. COMMENTS	THREAD
N-Acetylcysteine (NAC) -Inexpensive Treatment for Bipolar Depression	Bipolar Burble	41	http://natashatracy.com/bipolar-disorder/treat-bipolar-disorder-medication/
I Have Bipolar Depression -Should I Take an Antidepressant?	Bipolar Burble	48	https://natashatracy.com/bipolar-disorder/bipolar-depression-antidepressant/
Psychiatric Medications Don't Work- a Fact?	Bipolar Burble	81	https://natashatracy.com/mental-illness-issues/psychiatric-medications-dont-work-fact/
Fear of Bipolar Medication Treatment Changes	Bipolar Burble	52	https://natashatracy.com/treatment-issues/medication-changes/fear-bipolar-medication-treatment/
Pros and Cons of Electroconvulsive Therapy (ECT)	Bipolar Burble	30	https://natashatracy.com/treatment/neurostimulation-treatment/ect/pros-cons-electroconvulsive-therapy-ect/
Electroconvulsive Therapy Works (ECT, shock therapy)	Bipolar Burble	43	https://natashatracy.com/treatment/neurostimulation-treatment/ect/electroconvulsive-therapy-works-ect-shock-therapy/
Pourquoi le traitement ne suffit-il pas?	Le forum des bipotes	37	http://bipotes.leforum.eu/t12722-pourquoi-le-traitement-seul-ne-suffit-il-pas.htm
Abilify et experiences	Le forum des bipotes	30	http://bipotes.leforum.eu/t17011-abilify-et-experiences.htm
Toxicité du lithium	Le forum des bipotes	38	http://bipotes.leforum.eu/t11746-toxicite-du-lithium.htm
Que pensez-vous du Xeroquel/Seroquel?	Le forum des bipotes	347	http://bipotes.leforum.eu/t10689-que-pensez-vous-du-Xeroquel-Seroquel.htm
Traitement et delai d'efficacité. Lithium	Le forum des bipotes	30	http://bipotes.leforum.eu/t16116-Traitement-et-d-lai-d-efficacit.htm
EMDR	Le forum des bipotes	31	http://bipotes.leforum.eu/t15175-EMDR.htm
Depakote questionnement	Le forum des bipotes	38	http://bipotes.leforum.eu/t15634-Depakote.htm
Question sur la psychanalyse	Le forum des bipotes	70	http://bipotes.leforum.eu/t8000-question-sur-la-psychanalyse.htm

Continued

Table A.B.1: Overview of the online data used in the analysis of chapter 3

TITLE BLOG POST/ FORUM THREAD	NAME BLOG/ FORUM	NO. COMMENTS	THREAD
Abilify	Le forum des bipotes	127	http://bipotes.leforum.eu/t10110-Abilify-je-cherche-une-documentation-ou-site.htm
Lithium et Ramadan: question à Bipote	Le forum des bipotes	35	http://bipotes.leforum.eu/t5966-Lithium-et-Ramadan-question-a-Bipote.htm
Haute dose d'antipsychotique	Le forum des bipotes	32	http://bipotes.leforum.eu/t14658-Haute-dose-d-antipsychotique.htm
Xeroquel fait-il tant dormir?	Le forum des bipotes	39	http://bipotes.leforum.eu/t12533-xeroquel-fait-il-tant-dormir.htm
Le Cymbalta nouveau est arrivé	Le forum des bipotes	56	http://bipotes.leforum.eu/t994-le-Cymbalta-nouveau-est-arrive.htm
Question lithium	Le forum des bipotes	49	http://bipotes.leforum.eu/t13487-Question-lithium.htm

Table A.B.2: Overview of the online data used in the analysis of chapter 5

TITLE BLOG POST/ FORUM THREAD	BLOG/ FORUM	NO. COMMENTS	THREAD
À combien évaluez-vous votre humeur?	Troubles Bipolaires, Doctissimo	17 102	http://forum.doctissimo.fr/psychologie/Troubles-bipolaires/combien-evaluez-humeur-sujet_2161_1.htm
Comment gérer la fluctuation de l'humeur?	Troubles Bipolaires, Doctissimo	1829	http://forum.doctissimo.fr/psychologie/Troubles-bipolaires/gerer-fluctuation-humeur-sujet_2826_1.htm
Anybody struggling with return to work after a manic episode?	Bp Hope Forum	46	https://wwhttps://www.bphope.com/topics/discussion/anybody-struggling-with-return-to-work-after-a-manic-episode/w.bphope.com/topics/discussion/anybody-struggling-with-return-to-work-after-a-manic-episode/
Question about dissociation	Bp Hope Forum	31	https://www.bphope.com/topics/discussion/question-about-disassociation/
Does bipolar become harder to manage as we're growing older?	Bp Hope Forum	55	https://www.bphope.com/topics/discussion/does-bipolar-become-harder-to-manage-as-were-growing-older/

Continued

Table A.B.2: Overview of the online data used in the analysis of chapter 5

TITLE BLOG POST/ FORUM THREAD	BLOG/ FORUM	NO. COMMENTS	THREAD
What is your experience with a mixed state?	Bp Hope Forum	30	https://www.bphope.com/topics/discussion/what-is-your-experience-with-a-mixed-state/
Three Bipolar Symptoms No One Talks About	Bp Hope Forum	52	https://www.bphope.com/topics/discussion/three-bipolar-symptoms-no-one-talks-about/
Where were you when…?	Bp Hope Forum	41	https://www.bphope.com/topics/discussion/where-were-you-when/
Depressing Facts	Bp Hope Forum	31	https://www.bphope.com/topics/discussion/depressing-facts/
Your Photos	Bp Hope Forum	50	https://www.bphope.com/topics/discussion/depressing-facts/
Bipolar mania destruction having lived with untreated and misdiagnosed bipolar 1	Bp Hope Forum	35	https://www.bphope.com/topics/discussion/bipolar-mania-destruction-having-lived-with-untreated-and-misdiagnosed-bipolar-1/
Can’t seem to get anything done	Bp Hope Forum	30	https://www.bphope.com/topics/discussion/cant-seem-to-get-anything-done/
Why would someone suddenly hate someone they love?	Bp Hope Forum	88	https://www.bphope.com/topics/discussion/why-would-someone-suddenly-hate-someone-they-love/
Bipolar or not? Help!	Bp Hope Forum	30	https://www.bphope.com/topics/discussion/bipolar-or-not-help/
Early onset BP vs Late onset BP	Bp Hope Forum	30	https://www.bphope.com/topics/discussion/early-onset-bp-vs-late-onset-bp/
YOUR perception on living with bipolar	Bp Hope Forum	36	https://www.bphope.com/topics/discussion/your-perception-on-living-with-bipolar/
Sharing quotations	Bp Hope Forum	57	https://www.bphope.com/topics/discussion/sharing-quotations/

Appendix C

Original French quotes from Table 3.2

APPENDIX C

ORIGINAL FRENCH QUOTES FROM TABLE 3.2[18]

Table A.C.1 Original French version of the quotes provided in Table 3.2

CONTRIBUTOR NAME & DATE	**FORUM CONTRIBUTION**
Deepdeep, October 5, 2012	Ca c'est ma psy : Le lithium protège d'alzeimer. Pour ma mère ça à l'air d'être vrai jusque là... (…) Des fois je ne sais plus qui ou quoi croire...
nad, October 6, 2012	Pour alzeimer, j'ai entendu cela aussi, et pour la sclérose en plaques.
dallina, October 6, 2012	Mon psy du centre expert de Marseille dit que le lithium reconstitue les liaisons neuronales qui explosent sous l'effet de la bipolarité. Il protège aussi de la maladie d'alzeimer. Pour moi, la rebelle aux médicaments, ces arguments ont fait penchés la balance. J'ai accepté de reprendre un traitement au lithium. Je commence ce soir. Il m'a prescrit aussi du Xéroquel. Mais ça non ! je résiste encore.
Bipote,Admin_Bipote, October 6, 2012	Par ailleurs comme le dit Dallina, l'effet neuroprotecteur voire trophique du lithium mérite d'être mentionné, car il ouvre de nouvelles perspectives thérapeutiques. Une augmentation du volume de substance grise, notamment frontale a été observée chez les patients sous lithiothérapie. Un episode thymique est neurotoxique et sa repetition peut provoquer une atteinte neurobiologique.

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[18] The quotes are reproduced verbatim, so no spelling, grammar or punctuation errors have been corrected.

Appendix D

List of blog references used in chapter 4

APPENDIX D.

LIST OF BLOG REFERENCES USED IN CHAPTER 4

Fast J (2008) Omega 3 Fish Oil Tip. *Bipolar Happens!*, September 22, 2008. Available at: http://bipolarhappens.com/bhblog/omega-3-fish-oil-tip/ (accessed 3.12.2016)

Fast J (2010) Don't Forget Your Health Cards. *Bipolar Happens!,* May 6, 2010. Available at: http://bipolarhappens.com/bhblog/dont-forget-your-health-cards/#comments (accessed 3.12.2016)

Fast J (2015) What is the Difference between BIPOLAR DISORDER and Schizo-Affective Disorder? *Fast Talk,* December 31, 2015. Bipolar disorder Hope. Available at: http://www.bipolar disorderhope.com/blog/what-is-the-difference-bw-bipolar-disorder-and-schizo-affective-disorder/ (accessed at 3.12.2016)

Fast J (2016) BIPOLAR DISORDER Medications: Kaiser sues Pfizer over Misrepresentation of Gabapentine (Neurontin). *Bipolar Happens!*, October 17, 2016. Available at: http://bipolarhappens.com/bhblog/kaiser-sues-pfizer-over-mis-representation-of-gabapentine-neurontin/ (accessed 22.11. 2016)

Fast J (2017) Can We Diagnose Bipolar Disorder Using Eye Images? *Bipolar Happens!*, September 27, 2017. Available at: https://www.bipolarhappens.com/bhblog/can-we-diagnose-bipolar-disorder-using-eye-images/ (accessed 3.12.2017)

Fast J (2018) Bipolar Disorder and Brain Scans. *Bipolar Happens!*, July 18, 2018. Available at: https://www.bipolarhappens.com/bhblog/bipolar-disorder-and-brain-scans/ (accessed 25.9.2018)

Tracy N (2012) What to Do About Drug Tolerance. *Bipolar Bites*, May 30, 2012. Available at: http://www.healthline.com/health-blogs/bipolar-bites/what-do-about-drug-tolerance#1 (accessed 23. 04.2016)

Tracy N (2012) How Do You Know If It's the Therapy or the Drugs That Is Working? *Breaking Bipolar*, November 5, 2012. Available at: http://www.healthyplace.com/blogs/breakingbipolar/2012/11/how-know-therapy-or-drugs-working/ (accessed 9.09.2014)

Tracy N (2013) New Recommendations for Antidepressant Use in BIPOLAR DISORDER. *Bipolar Bites*, July 10, 2013. Available at: http://www.healthline.com/health-blogs/bipolar-bites/new-recommendations-antidepressant-use-bipolar-disorder#1 (accessed 23.04.2016)

Tracy N (2012) GlaxoSmithKline to Pay $3 Billion in Fines -So What? *Breaking Bipolar*, July 5, 2012. Available at http://www.healthyplace.com/blogs/breakingbipolar/2012/07/glaxosmithkline-pay-3-billion-fines-so-what/ (accessed 19.07.2016)

Tracy N (2011) Be a Good Mental Health (or Bipolar) Patient- Participate and Choose to Get Better. *Breaking Bipolar*. Reply to comment by Joel, June 30, 2011. Available at: http://www.healthyplace.com/blogs/breakingbipolar/2011/07/be-a-good-patient-choose-to-be-get-better/ (accessed 15.09.2014)

Tracy N (2016) Real Patient Experiences with ECT and Perspectives on ECT. *Bipolar Burble*, April 24, 2016. Available at: http://natashatracy.com/treatment/neurostimulation-treatment/ect/real-patient-experiences-ect-perspectives-ect/ (accessed 03.07.2016)

Summary

SUMMARY

In Western societies, expertise currently shapes people's lives to a significant degree, as people seek expert advice on a growing number of issues, such as how to avoid incurring financial debt, how to collaborate with colleagues with different personalities, how to maintain a healthy diet, or even how to select one's partner. Not only is there more expertise in our societies, but there are also more people who claim expertise as their prerogative. They do so not only due to having followed specific professional trajectories themselves and having received official accreditations, but increasingly by invoking various combinations of insights, skills, and experiences. At the same time, however, the relevance of expertise and the authority of experts have been intensely challenged. Thus, some have questioned the scientific grounds and the level of certainty based on which experts make their recommendations. Others have criticized the process of making decisions based on expert advice as undemocratic, arguing that experts as a specific social group are either detached from the realities of life and the preferences of the populations which become subject to their decisions, or that they are self-interested and primarily seek to maintain or further their already privileged position. Nowadays expertise is therefore both widely distributed and very much challenged.

This state of affairs is particularly poignant in the field of mental health, where medical knowledge and therapeutic approaches have been challenged both from within and from without the medical establishment, and where relations between people diagnosed and medical professionals have been rather contentious. The internet has generated various opportunities but also new challenges in this respect, as it has been increasingly used for the search and provision of mental health-related information, and as it has allowed people with the same diagnoses to come together, irrespective of their location. This has given rise to a set of intriguing questions about the identity of internet users who share and contribute to the development of knowledge, about the ways in which various aspects of their identity influence their online practices, and about the relations they develop with others who claim to have knowledge on the same topic, but from different perspectives.

In this dissertation I have studied how expertise on bipolar disorder is enacted on different American and French online platforms. In so doing, I have joined a long tradition of STS scholars, who have shown that knowledge is importantly shaped by the tools and instruments used in its development as well as by the norms and values of the communities of practice involved. I have combined these insights with perspectives acquired from medical sociologists and media scholars, who have focused on how the roles of patients and medical professionals have changed as a consequence of recent social

developments. A series of top-down and bottom-up initiatives has encouraged citizens to become informed about their health, and to play an active role in its management by taking on healthier lifestyles, by using various (wearable) technologies to keep track of health-related data, and by developing collaborative relationships with medical professionals. The internet has figured prominently in these initiatives as a therapeutic *and* as an educational tool, because it allows for the provision of online therapies, and because it affords quick and easy access to large amounts of information. It also enables people to contribute to new knowledge through various sharing practices, and many believe(d) that it would lead to the flattening of cultural differences.

This medium's potential has led many enthusiasts to assume that it will empower patients and enhance their engagement in knowledge processes, that it will improve relations between patients and medical professionals by facilitating communication between them, that it will help increase the popularity and authority of public institutions by facilitating transparency, accountability, and public dialogue. More recent studies on the role of the internet in mental health-related practices have revealed, however, a much more nuanced picture and have highlighted the need for more specific insights into how people in different functions and positions engage with the various technologies available online to make their knowledge on a particular mental health condition manifest. That is why this dissertation focuses on the following (sub)questions: (1) How do different stakeholders engage with online technologies to enact expertise about bipolar disorder? (2) How does the use of the internet in processes of knowledge evaluation and production allow for people diagnosed with bipolar disorder to re-position themselves in relation to medical professionals? (3) How do cultural markers shape the online enactment of expertise about bipolar disorder? (4) What individualizing or collectivity-generating effects does the internet have in relation to the online enactment of expertise about bipolar disorder?

I have answered these questions by collecting and analyzing online materials provided by two types of stakeholders: governmental agencies and people diagnosed with bipolar disorder in the U.S. and France. This approach has allowed me to bring into better relief how different types of constraints and resources shape the online enactment of expertise. Data were collected at different moments between June 2014 and September 2018 from different online platforms: official online pages of state agencies, blogs, and fora. In selecting the platforms, I aimed to reproduce the behaviors of average internet users interested in mental health-related information. I used the Google index as a relevance indicator and only selected online platforms which did not require any fee or registration to be accessed. The data consist of online texts, including hyperlinks and images, and have been analyzed using (combinations of) thematic analysis, computer-mediated discourse analysis, and conversation analysis.

In the introductory chapter, I explain why it is important to study expertise at this particular moment in time, focusing on the ways in which its meaning and relevance have been recently transformed and challenged. I also highlight the importance of understanding how the internet shapes the production, circulation, and evaluation of knowledge, and indicate what is specific about mental health and bipolar disorder to warrant a focused study thereof in relation to expertise. Furthermore, the main ways in which the concept of expertise has been approached in philosophy, sociology, and psychology are described. I build upon these theoretical perspectives using new insights acquired through the analysis of the data collected in order to develop a new approach to expertise. I understand expertise as a collective and practical achievement realized through coordination among stakeholders endowed with different types of knowledge, who occupy multiple, shifting positions in a complex ecosystem. This perspective has the advantage of drawing attention to the various interests and the multiple identities of a single individual and to the ways in which these may shape his/her contribution to the development of expertise. It also expands this concept, as it broadens the focus from relations between people who have expertise and people who need the advice and support of those who have it, to also include the relations that develop between people endowed with different types of expertise, who need to come together to solve problems which transcend the domains of their individual expertise and who, in so doing, may facilitate the development of a new type of expertise. The chapter concludes with a description of the methodological approach at the heart of this study and a reflection on some ethical issues I have encountered while conducting it.

In chapter two I show how two governmental agencies —the *National Institute of Mental Health* (NIMH) in the U.S. and *La Haute Autorité de Santé* (HAS) in France— enact expertise about bipolar disorder. These are highly authoritative institutions, which shape the ways in which bipolar disorder is understood by medical professionals, people diagnosed and the interested public. Even though they have considerable resources, which would allow them to deploy most online technologies available, these agencies face regulatory and socio-economic constraints, which limit their use of digital technologies. While both in the U.S. and France, the internet has been approached as a cost-effective means to provide mental health-related information, NIMH and HAS face two important challenges. First, in sharing their insights, they need to respect the accessibility recommendations for people with disabilities and for those using older-generation or less sophisticated technologies. Second, they need to take into account a social, professional, and cultural climate, where psychiatric approaches continue to be criticized, and where important struggles take place between different types of mental health professionals. To understand how these governmental agencies manage to convincingly enact expertise about bipolar disorder online, I have used an innovative methodological framework, which has allowed me to approach their online platforms as a complex set of public performances. The findings reveal that both NIMH and HAS are reluctant internet users, which have opted for noninteractive online platforms and static digital tools, such as pdf files and online text. In so doing, both agencies depict the knowledge currently available on bipolar disorder as precise and stable, all the while making several significant changes in the conceptualization of this condition. Thus, whereas the performative techniques they use are similar, NIMH and HAS differ in the aspects they choose to focus on in relation to bipolar disorder. I argue that this difference is informed by the distinct goals they need to address, as a consequence of the significant reforms undertaken in the mental healthcare system of their respective countries.

Chapter three marks a switch in focus, concentrating on people diagnosed with bipolar disorder and the different ways in which they enact expertise online. I show that medical perspectives on the effectiveness of therapeutic approaches used for this condition find their way from scientific publications to the (potential) recipients of such treatments, who transform them through their online engagements. This view is based on the analysis of two types of materials: highly-cited academic articles and abstracts, and online contributions provided by people diagnosed with bipolar disorder on blogs and fora. The findings show that the latter re-appropriate the notions of uncertainty, complexity, and individualization, which characterize current medical perspectives on the treatment of bipolar disorder, to achieve various pragmatic goals. The online affordances of blogs and fora allow for the longitudinal accumulation of numerous insights in the same online spaces. This, I argue, means that people diagnosed with bipolar disorder can move beyond the enactment of lay expertise and contribute to the development of what I have termed "digitally-informed hypotheses" about treatment effectiveness. Yet, for these hypotheses to lead to the development of the kind of insights that medical professionals take into account in their prescription practices, they need to be taken up by scientists. This shows that the degree to which people diagnosed with bipolar disorder can re-position themselves in relation to medical professionals through such contributions remains limited.

Chapter four examines the online and offline activities of two individual bloggers. At a time when people are urged to become informed about their health and to assume personal responsibility for it, I show how these bloggers have been able to become highly influential through their skillful use of the internet. By acquiring and enacting interactional expertise, they have managed to develop important ties with many other people diagnosed with bipolar disorder, who are avid readers of their blogs, as well as with medical professionals. On the one hand, their diagnosis has conferred them with legitimacy among people diagnosed and their families. Combined with their skillful use of the internet, this has enabled them to attract vast audiences. On the other hand, through the substantial medical knowledge they have acquired and due to their tremendous online popularity, they have successfully positioned themselves as representatives of people diagnosed with bipolar disorder and have become interesting collaborators for scientists and medical professionals. I argue that due to these various attributes and to the mediation work they engage in between people diagnosed and medical professionals, these bloggers have turned themselves into a new type of stakeholder, what I have called "online expert mediators". The high standing they enjoy is unprecedented among people diagnosed with bipolar disorder who lack medical training. Yet, this influential position has not been acquired through a subversive use of the internet, but through the strategic alliances these bloggers have forged with "traditional" experts. By studying how they enact interactional expertise, this chapter also makes a theoretical contribution, as it shows that this concept has a stronger bi-directional character than its proponents (Collins & Evans, 2002) have suggested, and as it highlights the important effects the medium has on the ways in which this specific type of expertise is made manifest.

In chapter five I scrutinize how current tendencies to focus on the health-related aspects which make people different rather than similar and the dominant incentives to responsibilize individuals about their health affect the development of lay expertise. This is important, because lay expertise is a collective concept, that depends for its development on the willingness of people diagnosed to share their insights with others with the same diagnosis. It is acquired as individuals learn to combine medical perspectives with knowledge developed through reflection on their personal experiences and from the strategies other people share. By studying the behaviors of online contributors diagnosed with bipolar disorder, I show that they enact solidarity with others with whom they share important commonalities. In so doing, they develop a new type of subgroup that I have termed "digital biocommunities". These communities come into being as people are brought together by a common diagnosis as well as by an increasing number of other relevant similarities, such as personal values and preferences and a common idiom of practice regarding their engagements with the technologies of online fora. While this shows that the internet has enabled the development of a new collective in relation to the enactment of expertise, digital biocommunities are based on practices of inclusion *and* exclusion. The findings presented in this last empirical chapter further reveal that the enactment of solidarity and lay expertise are closely linked, as online contributors incur various costs and perform affective labor in order to share their knowledge with those in need of it. Thus, not only do different individuals position themselves as lay experts in specific contexts, but they also contribute to the collective development of lay expertise, as new knowledge is distilled from their various sharing practices. A noteworthy contribution that this dissertation therefore makes is to show that despite fears that too strong a focus on individualization in healthcare would jeopardize solidarity, people diagnosed continue to understand and make sense of their condition relationally, through exchanges with various people in their lives. Furthermore, through their online exchanges, they manage to renounce, if only momentarily, the identity of vulnerable people, in need of assistance, and to reveal, instead, their ability to help and support others.

In the concluding chapter I reflect upon the significance of these findings by considering them against the backdrop of current developments in data analytics and artificial intelligence. Enthusiastic supporters of the latter believe algorithms and digital technologies may usurp the privileged positions humans have had for so long in the development of knowledge, thereby casting doubt about the meaning and relevance of human expertise. This dissertation has shown, however, that contrary to such expectations, context sensitivity and affective labor play an important role in the development and enactment of expertise. Substantial knowledge of bipolar disorder has had to be combined by online contributors with relevant insights about socio-cultural and personal factors. Thus, people diagnosed with this condition have made sense of it in ways which are shaped by how mental healthcare is organized in the countries they inhabit, by what medical professionals, family members, employers and friends expect of them, and by the aspects of their lives they find valuable and want to uphold despite their illness. The findings presented here have also shown that expertise bears the marks of important norms and values.

Many scholars and social commentators have feared that the incentives to responsibilize people for their health may prompt them to approach the provision of healthcare based on merit. An important contribution of this dissertation is to have shown instead that many online contributors derive important feelings of wellbeing from their ability to support others, that sharing one's plight online makes it more bearable. Solidarity is therefore a value worth further investigation in relation to the development and enactment of expertise. More consideration also needs to be given to the affective practices involved in the production of epistemic claims and expert recommendations, as the findings presented in this study have revealed how important emotional management is for interactions involving many people, who are endowed with different types of knowledge, who have different needs, and who pursue various goals.

Another significant contribution that this dissertation has made is to highlight how influential cultural factors remain when expertise about bipolar disorder is enacted online. By comparing French and American stakeholders, the analysis has revealed a number of important similarities and differences. Thus, both governmental agencies studied here have used similar performative techniques on their online platforms, and people diagnosed with bipolar disorder from both countries have contributed to the development of what I have called "digitally-informed hypotheses". They have also engaged in solidaristic practices. Nonetheless, the findings have also revealed that whereas online contributors in the U.S. prefer to share their insights on blogs, in France online fora are much more popular. While this may be due to the varying level of online visibility of the blogs and fora studied, more research is needed to better understand what accounts for such differences. Encouragements for people to become actively engaged in the management of their health combined with the possibility for them to become producers of health-related information through the use of interactive online platforms has led to the development of a new and highly successful type of entrepreneurs in the U.S., which I have called "online expert mediators". The absence of this form of entrepreneurial subjectivity from the French online mental health landscape may be due to a less pronounced focus on individual entrepreneurialism in France or to the fact that French medical professionals have managed to retain their authority and to maintain more cordial relations with patients. Another important cultural distinction that this dissertation has highlighted refers to different approaches and orientations to bipolar disorder. The two governmental agencies studied have re-conceptualized bipolar disorder in different ways, one promoting a neurological understanding and the other emphasizing its degenerative and highly suicidal character. Whereas many French online contributors diagnosed with this condition engaged in online exchanges to learn to better manage this condition in the context of rich professional and personal lives, many online participants in the U.S. were unemployed or had a hard time retaining their jobs. Furthermore, the latter seemed to have more fraught family relations and to be engaged in fewer social activities offline than their French counterparts. More studies are therefore needed to understand what accounts for these social differences on bipolar disorder and what measures would be most effective in addressing them.

Overall, this dissertation has shown that the online enactment of expertise is not a straightforward process, whereby offline practices and approaches are easily uploaded onto various online spaces, but it requires a lot of work, new skills and, at times, new or different collaborations between multiple stakeholders. Many have hoped that the internet would enhance the engagement of people diagnosed and enable them to develop more balanced relations with medical professionals, but the findings presented here suggest that such options are available only to some individuals and only in certain contexts. They have shown, however, that people diagnosed engage in more nuanced ways with the medical insights available to them, as they do not merely accept them as authoritative or automatically resist them. Instead, they re-appropriate them in creative ways, they adapt them to their particular goals and preferences. Furthermore, the internet has facilitated the development of a broad variety of exchanges, from rather brief and fleeting interactions among individuals interested in a few specific topics, to the rise of the highly popular and influential online expert mediators, to the development of digital biocommunities among people brought and held together by a growing number of commonalities.

The internet has been approached by many as a quick technological fix, as a medium through which mental health-related information and care could be provided in a cost-effective way to a large number of people. Yet, the findings presented here have shown that such approaches are bound to fail, if the social and cultural context in which the internet is to be used is not given sufficient consideration. At the same time, this dissertation indicates that fears that the use of the internet would have negative consequences on the health and wellbeing of people diagnosed by exposing them to inaccurate information and/or by increasing the risks of contentious relations with their medical professionals are not always well-founded. This does not mean, however, that this medium does not continue to pose important challenges. New approaches and policies are required in order to better tackle them, and these can mainly be developed by paying attention to the specific ways in which different types of users engage with the online affordances of various platforms. Furthermore, for the internet to achieve its potential in furthering patient engagement and improving the quality of their relations with medical professionals, important changes in the behaviors of relevant stakeholders need to occur. While people diagnosed need to become more familiar with scientific approaches and methodology, scientists and medical professionals have to be granted the time and opportunity to work on developing closer relations with their patients and study participants. The findings presented in this dissertation suggest that people diagnosed can handle numerous sources of ambiguity and can accept lower thresholds for the effectiveness of treatment, if the manner in which they are informed about them is not paternalistic and dismissive, but constitutes, instead, an open invitation to dialogue.

Samenvatting

SAMENVATTING

In het westen beïnvloedt expertise het leven van mensen in vergaande mate. Mensen schakelen de hulp in van experts voor een groeiend aantal problemen, waaronder het voorkomen van schulden, het volgen van een dieet, en het vinden van een partner. Vandaag de dag is er niet alleen meer expertise in onze samenleving, maar zijn er ook meer mensen die het claimen van expertise als hun recht zien. Zij doen dit niet alleen op basis van een opleiding die hen bepaalde rechten verleend, maar ook op basis van variërende combinaties van inzichten, vaardigheden en ervaringen. Tegelijkertijd worden de expertise en het gezag van experts in toenemende mate betwist en de wetenschappelijke gronden en het niveau van zekerheid waarop experts hun aanbevelingen doen ter discussie gesteld. Anderen stellen dat het besluitvormingsproces van experts ondemocratisch is en beargumenteren dat experts ver af staan van het dagelijks leven en de voorkeuren van de mensen die het effect van hun beslissingen moeten ondergaan. Daarnaast worden deze experts verweten dat ze alleen geïnteresseerd zijn in het verbeteren van hun reeds bevoorrechte positie. Tegenwoordig is expertise dus niet alleen wijdverspreid, maar staat het ook ter discussie.

Bovenstaande situatie is met name schrijnend in het domein van de geestesziekten, waar medische kennis en therapieën onder vuur liggen door mensen van zowel de gevestigde medische orde als daarbuiten, en waar de relatie tussen gediagnostiseerden en medische professionals omstreden is. Het internet heeft hiervoor zowel nieuwe mogelijkheden als uitdagingen opgeleverd. Het is gebruikelijk geworden om informatie over geestesziekten op het internet op te zoeken en aan te bieden. Daarnaast biedt het internet mensen met een soortgelijke diagnose de mogelijkheid samen te komen, ongeacht waar zij zich ter wereld bevinden. Dit leidt tot een aantal intrigerende vragen over de identiteit van internetgebruikers die bijdragen aan het ontwikkelen en delen van kennis, over hoe de verschillende aspecten van hun identiteit hun online gedrag beïnvloeden, en over de relaties die zij aangaan met andere personen die beweren kennis te bezitten over het zelfde onderwerp vanuit verschillende perspectieven.

In dit proefschrift heb ik bestudeerd hoe expertise op het gebied van bipolaire stoornissen vorm krijgt op verschillende Amerikaanse en Franse online platformen. Hiermee volg ik een traditie van STS-onderzoekers, die aangetoond hebben dat kennis vormgegeven wordt door de hulpmiddelen en instrumenten die gebruikt worden tijdens haar ontwikkeling, alsmede door de normen en waarden van de gemeenschappen die bij de ontwikkeling van deze kennis betrokken zijn. Ik heb deze inzichten gecombineerd met de perspectieven van medisch sociologen en mediawetenschappers, die onderzocht hebben hoe de rollen van patiënten en beroepsmedici veranderd zijn als gevolg van recente sociale ontwikkelingen. Diverse top-down en bottom-up initiatieven hebben burgers aangemoedigd informatie over hun gezondheid in te winnen, en om hier actief aan te werken door gezonder te leven, door informatie in te winnen door middel van nieuwe technologieën , en door samen te werken met medici. Het internet speelt een prominente rol hierin, als een therapeutisch en een educatief hulpmiddel, aangezien het niet alleen online therapieën aanbiedt maar ook snel en gemakkelijk toegang verschaft tot grote hoeveelheden informatie. Dit stelt mensen ook in staat bij te dragen aan nieuwe kennis door het delen van informatie. Velen zijn van mening dat dit tot een afvlakking van culturele verschillen zal leiden.

Voorstanders van dit nieuwe medium veronderstellen dat het de potentie heeft patiënten te emanciperen en hun betrokkenheid bij kennisprocessen zal vergroten. Daarnaast zou het de betrekkingen tussen patiënten en medici verbeteren en de communicatie tussen hen vergemakkelijken. Bovendien zou meer transparantie, verantwoordingsplicht, en publieke dialoog het gezag en de populariteit van openbare intstellingen bevorderen. Recent onderzoek naar de rol van het internet in geestelijk gezondheidszorgpraktijken laat echter een genuanceerder beeld zien. Deze studies benadrukken de noodzaak voor meer specifieke inzichten in hoe mensen in verschillende functies en posities diverse beschikbare online technieken gebruiken om kennis te vergroten over hoe een bepaalde geestesziekte zich manifesteert. Daarom stelt dit proefschrift de volgende (sub)vragen: (1) Hoe gebruiken verschillende belanghebbenden online technieken om expertise over bipolaire stoornissen aan te tonen? (2) Hoe stelt het gebruik van het internet bij het evalueren en produceren van kennis mensen (bij wie een bipolaire stoornis is vastgesteld) in staat om zich te herpositioneren vis-a-vis medici? (3) Hoe beïnvloeden culturele verschillen de manieren waarop expertise over bipolaire stoornis online wordt uitgeoefend? (4) Welke individualiserende of gemeenschapsvormende effecten heeft het internet als het op het het online uitoefenen van expertise over bipolaire stoornis aankomt?

Ik heb deze vragen beantwoord door het vergaren en analyseren van online bronnen die door twee soorten belanghebbenden werden aangeboden: overheidsinstanties en mensen bij wie bipolaire stoornis is vastgesteld in Amerika en in Frankrijk. Deze aanpak heeft mij in staat gesteld te tonen hoe verschillende middelen en beperkingen de online manifestatie van expertise beïnvloeden. De data is op verschillende tijdstippen tussen juni 2014 en september 2018 verzameld op diverse online platforms: officiële webpagina's van overheidsinstellingen, blogs, en fora. Bij het selecteren van de platforms heb ik geprobeerd het gedrag van de gemiddelde internetgebruiker die een interesse heeft in informatie over geestesziekten te reproduceren. Ik heb Google index gebruikt om een indicatie te krijgen van de relevantie van diverse platformen, en vervolgens heb ik enkel online platformen geselecteerd die geen registratie of betaald lidmaatschap vereisten.

De verzamelde data bestaat uit online teksten inclusief hyperlinks en afbeeldingen, en deze is geanalyseerd door (combinaties van) thematische analyse, computer geassisteerde discussie analyse, en conversatie analyse.

In de introductie leg ik uit waarom het belangrijk is om juist nu expertise te bestuderen, met een focus op de wijze waarop de betekenis en relevantie van expertise onlangs getransformeerd is en bekritiseerd wordt. Ik benadruk ook hoe belangrijk het is inzicht te verkrijgen in hoe het internet kennis vervaardigt, distribueert en doorontwikkelt, en ik leg uit wat geestesziekten en bipolaire stoornissen zo bijzonder maakt om er een onderzoek naar expertise aan te wijden. Verder beschrijf ik de voornaamste manieren waarop het concept expertise benaderd wordt in de filosofie, sociologie, en psychologie. Ik bouw voort op deze theoretische perspectieven en analyseer de verzamelde data om nieuwe inzichten te vergaren en een nieuwe benadering van expertise te formuleren. Ik zie expertise als een collectieve en praktische prestatie die het resultaat is van coördinatie tussen belanghebbenden met verschillende vormen van kennis, die meerdere verschuivende posities innemen in een complex ecosysteem. Dit perspectief heeft als voordeel dat de aandacht uitgaat naar de verschillende interesses en identiteiten van een individu, en hoe deze zijn of haar bijdrage aan het ontwikkelen van expertise vormgeeft. Dit perspectief is tevens een uitbreiding van het concept expertise, omdat het de focus verbreedt. Het kijkt niet alleen naar mensen met expertise en mensen die advies en ondersteuning van mensen met expertise nodig hebben, maar het richt onze blik ook op de relaties die zich vormen tussen experts van verschillende pluimage, die samen moeten werken om problemen op te lossen die hun individueel vakgebied overstijgen en die hiermee de ontwikkeling van een nieuw type expertise faciliteren. Het hoofdstuk sluit af met een beschrijving van de methodologische aanpak van deze studie en een reflectie op enkele ethische problemen die ik ondervond tijdens mijn onderzoek.

In hoofdstuk twee laat ik zien hoe twee overheidsinstanties - the *National Institute of Mental Health* (NIMH) in de Verenigde Staten, en *La Haute Autorité de Santé* (HAS) in Frankrijk— expertise met betrekking tot bipolaire stoornis bepalen. Dit zijn instituten met veel gezag, die de manier waarop bipolaire stoornis begrepen wordt door medici, patiënten, en een breder geïnteresseerd publiek vormgeeft. Hoewel zij beschikken over voldoende middelen, worden deze instanties beperkt door wetgeving en socio-economische factoren, die hun gebruik van digitale technieken beperkt. Hoewel in zowel de Verenigde Staten als in Frankrijk het internet beschouwd wordt als een efficiënte manier om geestesziekte-gerelateerde informatie beschikbaar te stellen, hebben NIMH en HAS twee belangrijke uitdagingen. Ten eerste moeten zij rekening houden met mensen die een beperking hebben of die verouderde en/of eenvoudige technologie gebruiken. Ten tweede moeten zij rekening houden met een sociaal-professioneel en cultureel klimaat waar psychiatrische benaderingen continu bekritiseerd worden en waar belangrijke worstelingen tussen diverse soorten professionals op het gebied van mentale gezondheid plaatsvinden. Om te begrijpen hoe deze overheidsinstanties in staat zijn overtuigend online expertise met betrekking tot bipolaire stoornis te bepalen, heb ik een innovatief methodologisch raamwerk gebruikt. Dit raamwerk stelde mij in staat om hun online platformen te benaderen als een complexe set van publieke performances. De bevindingen laten zien dat zowel NIMH als HAS terughoudend zijn als het aankomt op het gebruik van het internet en vaak voor niet-interactieve online platformen en statische digitale vormen kiezen, zoals PDF-bestanden en online tekst. Op deze manier wordt de kennis die beschikbaar is over bipolaire stoornis afgeschilderd als accuraat en stabiel, terwijl er daarnaast verschillende significante veranderingen in de conceptualisering van deze conditie doorgevoerd worden. Hoewel de performatieve technieken die zij gebruiken vergelijkbaar zijn, verschillen de MIMH en HAS in de manier waarop zij focussen in relatie met bipolaire stoornis. Ik beargumenteer dat dit verschil ontstaan is door de verschillende doelen die zij moeten nastreven, als gevolg van grootschalige veranderingen in de geestelijke gezondheidszorg in beide landen.

Hoofdstuk drie concentreert zich op mensen die gediagnostiseerd zijn met een bipolaire stoornis en de verschillende manieren waarop zij online expertise uitoefenen. Ik laat zien dat medische perspectieven op de effectiviteit van de therapieën voor deze conditie hun weg vinden via wetenschappelijke publicaties naar de (potentiele) ontvangers van deze behandelingen, die vervolgens deze kennis transformeren door hun online ontmoetingen. Deze conclusie is gebaseerd op een analyse van twee typen data: academische artikelen en samenvattingen met een hoge citatiescore en de online bijdragen van mensen gediagnostiseerd met bipolaire stoornis op fora en blogs. De bevindingen laten zien dat laatstgenoemden noties van onzekerheid, complexiteit en individualisering die de huidige medische perspectieven op het behandelen van bipolaire stoornis karakteriseren, zich toe-eigenen om verschillende praktische doelen te realiseren. Online blogs en fora maken een longitudinale accumulatie van tal van inzichten op dezelfde online ruimten mogelijk. Dit betekent, zo beargumenteer ik, dat mensen die gediagnostiseerd zijn met bipolaire stoornis verder kunnen gaan dan het uitoefenen van ‘leken-expertise’ door bij te dragen aan wat ik ‘digitaal–geïnformeerde hypotheses’ over de effectiviteit van een behandeling noem. Echter voordat deze hypothesen tot nieuwe inzichten leiden die medici in beschouwing kunnen nemen in het voorschrijven van medicijnen, moeten ze door wetenschappers onderzocht worden. Dit laat zien dat de mate waarin mensen die gediagnosticeerd zijn met bipolaire stoornis zich kunnen herpositioneren vis-a-vis medici middels zulke bijdragen, beperkt is.

Hoofdstuk vier onderzoekt de online en offline activiteiten van twee individuele bloggers. In een tijd waarin mensen aangemoedigd worden om informatie in te winnen over hun gezondheid en om daar verantwoordelijkheid over te nemen, laat ik zien dat deze bloggers veel invloed hebben door handig gebruik te maken van het internet. Door het verkrijgen en bepalen van interactionele expertise hebben zij het voor elkaar gekregen om belangrijke relaties te ontwikkelen met medici en mensen met bipolaire stoornis, die gretige lezers zijn van hun blogs. Aan de ene kant geeft de diagnose hen een mate van legitimiteit onder gediagnostiseerde mensen en hun families. In combinatie met hun slimme gebruik van het internet heeft dit hen in staat gesteld een groot publiek aan te trekken. Aan de andere kant hebben zij door het ontwikkelen van medische kennis en het verkrijgen van online populariteit zichzelf kunnen positioneren als vertegenwoordigers van mensen die gediagnostiseerd zijn met bipolaire stoornis, en zijn zo interessante medewerkers geworden voor wetenschappers en medici. Ik beargumenteer dat vanwege deze verschillende eigenschappen en door de bemiddeling die zij doen tussen mensen die gediagnostiseerd zijn en medici, dat deze bloggers zelf een nieuw soort belanghebbenden zijn geworden, wat ik 'online expert mediators' noem. De reputatie die zij genieten onder mensen gediagnostiseerd met bipolaire stoornis die geen medische training hebben genoten, is zonder precedent. Toch is deze positie niet ontstaan door subversief gebruik van het internet, maar door de strategische samenwerking tussen deze bloggers en 'traditionele' experts. Door te bestuderen hoe zij interactionele expertise bepalen, maakt dit hoofdstuk ook een theoretische bijdrage. Het laat zien dat dit concept een sterker bi-directioneel karakter heeft dan haar voorstanders (Collins & Evans, 2002) hadden voorgesteld, en dat het de belangrijke effecten benadrukt die het medium heeft op de manieren waarop deze specifieke variant van expertise zich manifesteert.

In hoofdstuk vijf onderzoek ik hoe de ontwikkeling van 'leken-expertise' beïnvloed wordt door de huidige tendens om die gezondheids-gerelateerde aspecten te benadrukken die mensen van elkaar onderscheiden, en de drijfveer om personen verantwoordelijk te maken voor hun eigen gezondheid. Dit is belangrijk, aangezien leken-expertise een collectief concept is. De ontwikkeling van leken-expertise is afhankelijk van de bereidheid van mensen om hun inzichten met anderen met dezelfde diagnose te delen. Het kan worden verworven als individuen in staat zijn om medische perspectieven te combineren met kennis verworven door het reflecteren op hun persoonlijke ervaringen en uit de strategieën die andere mensen delen. Door het gedrag van online bijdragers, die gediagnosticeerd zijn met bipolaire stoornis, te bestuderen, laat ik zien dat ze solidair zijn met anderen met wie ze belangrijke overeenkomsten delen. Daarbij ontwikkelen ze een nieuw type subgroep dat ik 'digitale biogemeenschappen' noem. Deze gemeenschappen ontstaan als mensen worden samengebracht door een gemeenschappelijke diagnose en door een toenemend aantal andere relevante gelijkenissen, zoals persoonlijke waarden en voorkeuren en een gemeenschappelijk idioom met betrekking tot hoe zij in de praktijk omgaan met de technologieën van online fora. Hoewel hieruit blijkt dat het internet de ontwikkeling van een nieuw collectief mogelijk heeft gemaakt met betrekking tot het vaststellen van expertise, zijn digitale biogemeenschappen gebaseerd op praktijken van inclusie *en* uitsluiting. Uit de bevindingen in dit laatste empirische hoofdstuk blijkt verder dat het vaststellen van solidariteit en lekendeskundigheid nauw met elkaar zijn verbonden, aangezien online bijdragers verschillende kosten maken en affectieve arbeid verrichten om hun kennis te delen met mensen die daar behoefte aan hebben. Zo positioneren verschillende individuen zich niet alleen als lekendeskundigen in specifieke contexten, maar dragen ze ook bij aan de collectieve ontwikkeling van lekenexpertise, omdat nieuwe kennis wordt gedistilleerd uit de verschillende praktijken waarmee zij informatie delen. Een opmerkelijke bijdrage die dit proefschrift daarom maakt, is dat het laat zien dat, ondanks de vrees dat een te sterke focus op individualisering in de gezondheidszorg de solidariteit in gevaar zou brengen, mensen die gediagnosticeerd zijn in staat blijven hun conditie relationeel te begrijpen en in een context te plaatsen middels het uitwisselen van ervaringen met verschillende mensen in hun leven. Bovendien slagen ze er via hun online uitwisselingen in om de identiteit van een kwetsbaar persoon die hulp nodig heeft af te zweren en hun vermogen om anderen te helpen en te ondersteunen te tonen, al is het maar voor even.

In het afsluitende hoofdstuk denk ik na over de betekenis van mijn bevindingen door ze te beschouwen tegen de achtergrond van huidige ontwikkelingen op het gebied van data-analyse en kunstmatige intelligentie. Enthousiaste aanhangers van kunstmatige intelligentie zijn van mening dat algoritmen en digitale technologieën de bevoorrechte posities die mensen lange tijd hebben gehad in de ontwikkeling van kennis kunnen overstijgen. Hiermee zaaien zij twijfel over de betekenis en relevantie van menselijke expertise. Dit proefschrift heeft echter aangetoond dat contextgevoeligheid en affectieve arbeid, in tegenstelling tot bovengenoemde verwachtingen, een belangrijke rol spelen bij het ontwikkelen en vaststellen van deskundigheid. Substantiële kennis van bipolaire stoornis moest door online bijdragers gecombineerd worden met relevante inzichten over socio-culturele en persoonlijke factoren. Op deze manier begrijpen mensen gediagnosticeerd met een bipolaire stoornis hun aandoening op een manier die is gevormd door de wijze waarop de mentale gezondheidszorg is georganiseerd in de landen waarin zij wonen, door de verwachtingen van medische professionals, familieleden, werkgevers en vrienden en door aspecten van hun leven die ze waardevol vinden en die ze, ondanks hun ziekte, willen verdedigen. Uit de hier gepresenteerde bevindingen is ook gebleken dat deskundigheid sporen bevat van belangrijke normen en waarden.

Veel wetenschappers en sociale commentatoren vrezen dat de tendens om mensen verantwoordelijk te maken voor hun gezondheid ertoe leidt dat gezondheidszorg verstrekt wordt op basis van verdienste. Echter een belangrijke bijdrage van dit proefschrift is dat veel online bijdragersbelangrijke gevoelens van welzijn ontlenen aan hun vermogen om anderen te ondersteunen en dat het delen van hun soms lastige situatie deze draaglijker maakt. Solidariteit is daarom een waarde die verder onderzoek verdient met betrekking tot het ontwikkelen en vaststellen van deskundigheid. Er moet ook meer aandacht worden geschonken aan de affectieve praktijken die nodig zijn voor de productie van epistemische beweringen en deskundige aanbevelingen, aangezien de bevindingen in deze studie aantonen hoe belangrijk 'emotioneel management' is voor interacties tussen mensen met verschillende soorten kennis en behoeftes en die verschillende doelen nastreven.

Een andere belangrijke bijdrage van dit proefschrift is dat het toont hoe invloedrijk culturele factoren blijven wanneer deskundigheid over bipolaire stoornis online wordt uitgeoefend. Door het vergelijken van Amerikaanse en Franse stakeholders, heeft de analyse een aantal belangrijke overeenkomsten en verschillen blootgelegd. Beide overheidsinstanties gebruiken soortgelijke performatieve technieken op hun online platforms en mensen gediagnosticeerd met bipolaire stoornis in beide landen hebben bijgedragen aan de ontwikkeling van wat ik 'digitaal-geïnformeerde hypotheses' heb genoemd. Zij hebben zich ook beziggehouden met solidaire praktijken. Desalniettemin tonen de bevindingen ook dat online bijdragers in de VS hun inzichten liever op blogs delen terwijl in Frankrijk online fora populairder zijn. Hoewel dit kan komen door het wisselende niveau van online zichtbaarheid van de blogs en fora, is er meer onderzoek nodig om beter te begrijpen wat de oorzaak is voor dergelijke verschillen. Het aanmoedigen van mensen om actief betrokken te raken bij het managen van hun gezondheid in combinatie met de mogelijkheid dat zij producenten worden van gezondheidsgerelateerde informatie door het gebruik van interactieve online platforms, heeft tot de ontwikkeling van een nieuw en zeer succesvol type ondernemers in de VS geleid, die ik 'online expert bemiddelaars' noem. Het ontbreken van deze vorm van ondernemende subjectiviteitin het Franse online Mental Health-landschap kan te wijten zijn aan een minder uitgesproken focus op individueel ondernemerschap in Frankrijk, of aan het feit dat Franse medische professionals erin zijn geslaagd hun gezag te behouden en meer persoonlijke relaties met patiënten te onderhouden. Een ander belangrijk cultureel onderscheid dat dit proefschrift heeft benadrukt, verwijst naar de verschillende benaderingen van en oriëntaties op bipolaire stoornis. De twee overheidsinstanties die ik bestudeerd heb, her-conceptualiseren bipolaire stoornis op verschillende manieren. Waar de een een neurologische begrip benadrukt, legt de ander de nadruk op haar degeneratieve en zeer suïcidale karakter. Terwijl veel Franse online bijdragers gediagnosticeerd met deze aandoening zich bezighouden met online uitwisselingen met als doel te leren hoe zij beter met deze aandoening kunnen omgaan in de context van een rijk professioneel en persoonlijk leven, waren veel online deelnemers in de VS werkloos of hadden moeite hun werk te behouden. Bovendien leek deze laatste groep vaker moeizame familierelaties te hebben en aan minder sociale activiteiten deel te nemen dan hun Franse tegenhangers. Er is daarom meer onderzoek nodig om te begrijpen wat de oorzaken zijn voor deze sociale verschillen jegens bipolaire stoornis en welke maatregelen het meest effectief zijn bij het aanpakken ervan.

Over het algemeen heeft dit proefschrift aangetoond dat het online uitoefenen van expertise geen eenvoudig proces is waarbij offline praktijken en benaderingen gemakkelijk kunnen worden geüpload naar verschillende online ruimtes, maar dat dit veel werk, nieuwe vaardigheden en soms nieuwe of verschillende samenwerkingen tussen belanghebbenden vergt. Velen hoopten dat het internet mensen die gediagnosticeerd zijn meer zou betrekken in het managen van hun gezondheid en hen beter in staat zou stellen meer evenwichtige relaties met medische professionals te ontwikkelen. Echter, de bevindingen gepresenteerd in dit proefschrift suggereren dat dergelijke opties alleen beschikbaar zijn voor bepaalde individuen in specifieke contexten. Het werd duidelijk dat mensen die gediagnosticeerd zijn zich op genuanceerde manieren verhouden met de medische inzichten die voor hen beschikbaar zijn, omdat ze de inzichten niet zonder meer accepteren of zich er automatisch tegen verzetten. In plaats daarvan maakten ze ze zich deze inzichten op creatieve manieren eigen en pasten ze deze aan hun specifieke doelen en voorkeuren aan. Bovendien heeft het internet de ontwikkeling van een breed scala aan uitwisselingen vergemakkelijkt, variërend van vrij korte en vluchtige interacties tussen individuen die geïnteresseerd zijn in een paar specifieke onderwerpen, tot de opkomst van de zeer populaire en invloedrijke online expert mediators en de ontwikkeling van digitale biogemeenschappen van mensen die door een groeiend aantal gemeenschappelijke delers zijn samengebracht en bijeengehouden.

Het internet wordt door velen benaderd als een snelle technologische oplossing, als een medium waarmee geestelijke gezondheidsgerelateerde informatie en zorg op een kosteneffectieve manier kunnen worden verstrekt aan een groot aantal mensen. Uit de bevindingen van dit proefschrift is echter gebleken dat dergelijke benaderingen onvermijdelijk mislukken als de sociale en culturele context waarin het internet wordt gebruikt onvoldoende in overweging wordt genomen. Tegelijkertijd geeft dit proefschrift aan dat de vrees dat het gebruik van internet negatieve gevolgen zou hebben voor de gezondheid en het welzijn van mensen die gediagnosticeerd worden door hen bloot te stellen aan onnauwkeurige informatie en/of door het verhogen van de risico's van moeilijke relaties met hun medische professionals, niet altijd gegrond zijn. Dit betekent echter niet dat dit medium niet tot nieuwe uitdagingen zal leiden. Nieuwe benaderingen en beleidsmaatregelen zijn nodig om deze uitdagingen beter aan te pakken en deze kunnen voornamelijk worden ontwikkeld door aandacht te schenken aan de specifieke manieren waarop verschillende soorten gebruikers omgaan met de mogelijkheden die verschillende online platformen hen biedt. Bovendien moeten er belangrijke veranderingen optreden in het gedrag van relevante betrokkenen, zodat het internet zijn potentieel kan bereiken om de betrokkenheid van patiënten te bevorderen en de kwaliteit van hun relaties met medische professionals te verbeteren. Waar gediagnosticeerde mensen beter vertrouwd moeten raken met wetenschappelijke benaderingen en methodes, moeten wetenschappers en medische professionals de tijd en de kans krijgen nauwere relaties te onwikkelen met hun patiënten en respondenten in hun onderzoek. De bevindingen in dit proefschrift suggereren dat gediagnosticeerde mensen in staat zijn om te gaan met bronnen van onzekerheid of dubbelzinnigheid, en dat zij lagere drempels voor de effectiviteit van de behandeling kunnen accepteren, mits de manier waarop zij hierover geïnformeerd worden niet paternalistisch is, maar uitnodigt tot een open dialoog.

Valorization addendum

VALORIZATION ADDENDUM

Work on this dissertation has unfolded in a context where the internet has been used more and more for health-related purposes by citizens, governmental agencies, and by medical institutions. The number of mobile health applications available as well as the number of people using them have increased tremendously; electronic patient records have been introduced in many countries; and numerous online platforms have been developed to bring together patients, health activists, caregivers, medical professionals, and researchers. The findings presented in this dissertation show that making (medical) expertise available, recognizable, and useful for online audiences is no easy feat. On the contrary, it involves numerous adaptations and transformations of various offline approaches, tools, and practices; and it requires the collaboration of many different types of stakeholders, numerous skills, and complex negotiations.

Many enthusiasts hoped that the internet would be a medium through which health-related information could be successfully provided to large audiences. Yet, one of the main merits of the study I conducted is to have drawn attention to the significant influence the type of online platforms, their affordances, and architecture have in regard to how knowledge can be shaped and made available to specific audiences. At the same time, it has highlighted the important role new stakeholders play in such a context and has identified some of the values that shape how knowledge is made available as well as how new insights are produced online. This dissertation also shows that far from being a cheap, easy, unproblematic solution, the internet is a medium that requires a lot of work in order to be made to benefit people with health concerns and society overall. This is an important sobering call at a time when governments continue to expect that the internet would: broaden the availability of healthcare in remote areas; help improve the quality of healthcare; reduce the tremendous financial burden that expensive medical interventions and an ageing population are claimed to place on national budgets.

In discussing the overall societal benefits of my study, this addendum is organized in three parts. First, I highlight several reasons that make me rather skeptical about such a ‘valorization’ exercise. Second, I discuss some of the efforts made to disseminate the findings of this research beyond the academic community. Third, a set of recommendations is developed for scholars interested to study online practices as well as for important stakeholders identified while conducting this study. These include: people diagnosed and caregivers who consider using or who use the internet for health-related information, mental health professionals, policy makers, and governmental agencies that want to use their online platforms to more successfully communicate with the public.

1. VALORIZATION AND MY DISCONTENTS

It would be naïve to believe that there has ever been a time when scientists, researchers, or public intellectuals have not had to step out of their laboratories, ivory towers or 'margins' to engage with broader audiences. However, over the last three decades, initiatives by which scholars are called to account for the relevance of their work outside of academia have grown. Reflecting this trend, Maastricht University has introduced a requirement whereby doctoral candidates must include a valorization addendum in their dissertation. In it, knowledge valorization is defined as "the process of creating value from knowledge, by making knowledge suitable and/or available for social (and/or economic) use and by making knowledge suitable for translation into competitive products, services, processes and new commercial activities" (Regulation governing the attainment of doctoral degrees at Maastricht University, 2018, art. 23: 47). I am rather skeptical about such an approach, because it implies that there may be forms or types of knowledge that are not valuable. The regulation assumes, despite historical evidence to the contrary, that the relevance of any given piece of knowledge can be accurately known or assessed relatively close to the moment when it has been produced. Furthermore, even though this definition of valorization seems to focus on the social implication of research, in practice its economic uses are prioritized, which can also be inferred from the "competitive products" mentioned in the last part of the quote provided. This understanding of valorization prioritizes thus a for-profit logic to the detriment of perspectives that could promote other values, such as social justice, equality, solidarity.

Yet, there is a certain alignment between the valorization ethos that has rendered this addendum necessary and the "democratization" of knowledge that I studied. Many of the online practices discussed in my dissertation and this addendum are the (side) effects of a growing trend towards individual responsibilization and commodification. In it, individuals are approached as autonomous producers and consumers, who are responsible for the choices they make and need to account for them, particularly when they involve the use of public funds. While the general population is increasingly called to answer for the costs their un/healthy lifestyles place on national budgets, researchers need to account for the public funds they receive, and increasingly to defend the *raison d'être* of their discipline, particularly when the insights it can contribute to are less palpable and hard to quantify (Nussbaum, 2010). Commodification tendencies are present in both situations as well. Many of the online insights provided by people diagnosed with bipolar disorder discussed in this dissertation can and are commodified into a variety of data products, that pharmaceutical companies may purchase for targeted marketing, or that hospitals, insurance companies, credit controllers or research institutes acquire for other purposes. Similarly, researchers are increasingly prompted to consider the applicability of the findings they may arrive at, and how they may contribute to the accumulation of capital (Halffman & Radder, 2015). This is obvious also from the definition of valorization presented above.

The focus on competition and commodification at the heart of valorization is deeply worrying. In a world where universities are allocated funds based on quantified markers that grossly oversimply the activities and societal contribution of such institutions, researchers must compete for scarce research funds, with limited time to allow themselves to be inspired, to give their thoughts a chance to 'brew', and to explore multiple options or new areas of interest. At the same time, while collaborations with industry and other partners are encouraged, little money is allocated for collaborative research, so that researchers from the same or similar disciplines could actually work together rather than compete against each other. To be clear, there is nothing wrong with a bit of healthy competition, nor with trying to assess activities and output using a great variety of metrics in an attempt to acquire a better or more complex understanding of a given phenomenon. What I believe is wrong is reducing the societal benefits of research and education mainly to elements that can be quantified, and, to make matters worse, approaching such markers as if they had a direct relation to the actual benefits rather than seeing them as the result of negotiations, as the product of specific values, measurement instruments, power and epistemic relations at this specific time in Western countries. Thus, such an approach does not actually have the 'truth' value that it is often ascribed, and it also distracts from aspects that may be more important or which may have more lasting effects. Using quantified metrics, institutions can keep track of the number of public events researchers have attended and of the number of non-academic publications they have written. Yet, despite so-called advances in psychometrics, such an approach can still not account for how such encounters or texts may inspire or motivate people, or how they may change their perspective on a given topic. Nevertheless, I do believe that researchers have a responsibility to make their knowledge available to large audiences, that they should be involved members of the communities and societies they live in, and that the knowledge they produce should benefit as many people as possible. This is what has made writing this valorization addendum truly meaningful for me.

2. DISSEMINATION OF RESULTS

From the very beginning, I imagined the key audiences of this study to consist not only of academics, but to include people diagnosed with bipolar disorder and other (mental) health conditions, caregivers, interested citizens, medical professionals, activists, and policy makers. To ensure that the insights acquired spoke to the interests of such broad audiences, I attended several events at different stages of my research. In so doing, I have used these activities as opportunities for me as a scholar to speak *with* rather than merely *to* non-academic audiences.

In 2015, I presented some preliminary findings at the international conference "Patients in the Health Ecosystem: Information Challenges and Communication Issues" that was held in Paris, and which brought together scholars, patients, health activists, and governmental officials. In the talk I gave, I highlighted several similarities and differences regarding the ways in which knowledge on bipolar disorder was made available on French and American online platforms. The questions and insights acquired from the other participants were used to guide my analysis in the later stages of this study. Having thus acquired a better understanding of the difficulties people diagnosed encountered when using the internet for health-related purposes, I paid more attention to the type of audience that was addressed on the online platforms I studied and to the level of education and (good) health required for it to be easily and correctly processed. In order to answer some of the concerns raised by the people diagnosed and patient activists I met, I subsequently focused more on the regulations available in France and the U.S. and how they shaped how governmental agencies shared their insights online.

In June 2017, I was invited to give a workshop in Maastricht on "The digitalization of healthcare" by the German Academic Scholarship Foundation. This gave me the opportunity to present my findings to a group of students and young professionals from various disciplines, including medicine, psychology, mathematics. On this occasion, I also prepared materials and exercises for the workshop participants to engage in a critical discussion on the advantages and disadvantages of using the internet in the provision of healthcare. In so doing, I helped future professionals and scholars to better understand some of the reasons that prompt people to search for health-related information online, and to better grasp the advantages and disadvantages of using the health-related services that big technological companies, such as Google or Facebook, make available. Sharing my findings with future medical professionals made them more aware of the different needs and expectations people diagnosed often have from their medical encounters. It also helped them realize that people sharing the information they acquire online with medical professionals is generally not meant as a challenge to their authority, but is often intended to improve the quality and outcome of their interactions. The exercises and discussions I had with students from non-medical disciplines helped them contextualize the use of the internet for health-related purposes, and prompted them to think more critically about the online provision of health-related information, and how online contributions could be used by third parties. Talking about the challenges people with mental health diagnoses encounter online and offline also rendered the students more aware of how stigma continues to affect people diagnosed with mental health conditions. I also encouraged them to consider more carefully the role social, economic, and cultural factors can play in the onset and trajectory of such conditions.

As the analysis presented in this dissertation had been completed and as my doctoral study was drawing to an end, I engaged in several other activities in order to disseminate the most important findings. In March 2018, I participated in a round-table discussion and gave a poster presentation at the British Academy European Research Council Workshop "Mental Health Policy and Social Science Practice: Enhancing Engagement and Expertise", that was held in Edinburgh. The workshop brought together academics, politicians, patients, and caregivers. In October 2018, I gave a presentation titled *"Digitale biogemeenschappen: Gemeenschap vormen en gewoontes delen op blogs en fora door mensen met een bipolaire stoornis"* (Digital biocommunities: community-building and sharing practices on blogs and fora among people diagnosed with bipolar disorder) at one of the EuroScience Open Forum (ESOF) Lectures organized for members of the public by the *Universitair Centrum Sint-Ignatius* in Antwerp. This enabled me to engage in a fruitful exchange with caregivers and medical professionals, including psychiatrists, psychologists, and general practitioners, on how the use of the internet could foster solidarity among people diagnosed with bipolar disorder. It also allowed me to better understand that the internet had come to be perceived as posing an important threat to the professional authority of some of these people and to have a dialogue about the types of patient and professional forms of online engagement they would support. On April 23, 2019 I attended a consultation of the Dutch Youth Health Council, where young researchers were invited to engage in an open discussion and to make recommendations on the ethical and responsible use of online applications and wearable technologies for health-related purposes at the initiative of Bruno Bruins, the Dutch Minister of Medical Care. The findings presented in this dissertation enabled me to make fruitful contributions to the discussion, some of which were taken up in the final report (forthcoming).

Apart from talks and presentations, I have shared the insights I acquired while conducting my research by writing for non-academic audiences. In December 2017, I wrote an essay titled "Digital morning, or manic by design", in which I explored the risks and benefits of an increased use of online applications and wearable technologies. It won the Visionary Essay Competition (2018) at the inauguration of the Institute of Data Science at Maastricht University and was made available for broader audiences to read on the website of this institute. I also wrote a column on the use of the internet for health-related purposes in the popular philosophy magazine *Wijsgerig Perspectief* (2019).

3. RECOMMENDATIONS

3.1 Recommendations for scholars studying online practices

Work on this dissertation has made me aware of several important difficulties that one can encounter when planning to study online practices. Acquiring permission to conduct virtual ethnography has not been possible in my study, as the online platforms owners- be they private businesses or public institutions- were not willing to support third-party research. Furthermore, while my research project was unfolding, it became more and more necessary for scholars to ask permission from platform owners to use online data, even when such data are publicly and openly available, and when they consist of the online contributions of platform users. To prevent such problems, the following may help:

- Contact with the online platforms of interest should be established and permission to collect data should be obtained as early as possible, to make it less difficult to bring changes to the overall project, should such permission not be granted. Having already developed personal contacts with people affiliated with the platform may facilitate such negotiations. Since the first point of access are often call center employees, who may not have the authority to engage in such negotiations, it may be more effective to send a letter written by the legal department of the university or research institute to the company that owns the online platform, in which general information about the study, its ethical approval status, and the type of data that will be collected from the platform are described.
- The Terms of Use of the platforms studied should be checked frequently and recorded or captured for future reference. Ideally the agreement with the online platform should also stipulate that no future changes may affect the research activities agreed upon or, at least, that information about any such changes will be timely provided.
- Legal counsel should be pre-emptively sought when such data are collected, analyzed, and intended for publication across multiple countries, to avoid any legal hassle due to differences in national legislation and regulatory practices.

3.2 Recommendations for people diagnosed and caregivers

My study has shown that there are important differences among online platforms regarding the type of content on mental health they make available as well as about the level of engagement and the forms of interaction they enable among users. Furthermore, the findings presented in my dissertation have also revealed that interactions on different online platforms are shaped by specific values, with solidarity often being enacted by online contributors on specific fora. The following may help people diagnosed and their caregivers in their online quests:

- Individuals diagnosed or caregivers require patience and perseverance when searching for online platforms that provide (mental) health-related information in ways that speak to their needs and preferences. Depending on how the algorithm of the search engine they use is optimized, they may need to search past the first few pages of results to find online spaces where they feel comfortable or which provide the insights they are looking for.
- Information about medical and other therapeutic approaches should be collected from multiple online platforms and the accounts of multiple people diagnosed should be read to acquire a better understanding of the ways in which they are prescribed and of the various side-effects they may have.
- Even though it may be difficult at times, online (mental) health-related insights should be consumed with a critical attitude. Information about the source of these insights, the methods by which they were arrived at, when, and by whom should be minimal criteria to bear in mind.
- The lack of online accounts about certain physical experiences, mental states or behaviors when undergoing a particular mood episode or when taking a certain medication should not automatically disqualify or cast doubt about them. For instance, the fact that no online testimonies are found that attest to an increase in alcohol consumption when taking a particular antidepressant does not necessarily mean that one is not telling the truth or that this is an invalid inference. Rather, it should lead to a more careful observation of this experience and to open and elaborate consultations with different medical professionals. At the same time, the description of mental states and of the effects and side-effects of medications should be done in a responsible manner and after careful consideration, knowing that people experiencing different moods, having access to different types of healthcare, and in different socio-economic positions may have access to them.
- Caution should be used when providing (mental) health-related information online. Since some of this information may also affect others in one's family or social circle, talking to them about it in advance may provide some clarity

or some sort of a communal agreement as to what information is seen as belonging strictly to the individual and which insights are understood to be collectively owned by that specific group. When such consultations are not desired or possible and when online engagement is intended to be private, people should first devote some time and effort to finding out how they can increase the chance of protecting their privacy rather then immediately conducting online searches, reading, watching, or describing their difficulties and dilemmas.

- The Terms of Use rubric of each platform should be carefully read before sharing information online. Even though some online platforms may seem safe places, sanctuaries where one can find refuge, understanding, and respite, only detailed information about the data collection processes on these platforms and their subsequent use can indicate to what extent this is truly the case. Furthermore, such policies can change, particularly in the case of mergers or acquisition by other companies, so remaining alert to any modifications would be an appropriate, albeit time-consuming attitude.

3.3 Recommendations for medical professionals

My dissertation has shown that people diagnosed can make important contributions in areas where the currently available medical knowledge is uncertain or insufficient. Such contributions are often the result of detailed self-monitoring practices and of the avid consumption of relevant medical information. These practices are undertaken out of a desire to improve one's self-knowledge and ability to manage one's condition, but are also informed by the need to convince medical professionals about the side-effects they experience and about the advantages of a desired change of medication. Furthermore, the findings of my study have shown that people diagnosed have a broad understanding of what constitutes treatment effectiveness, whereby the ability to continue to engage in various activities, ranging from fulfilling one's familial and professional duties, to participating in one's favorite hobbies, play an important role. From this point of view, their online search for mental health-related information is often motivated by the limited time they have at their disposal to discuss such matters with medical professionals or is due to the latter's unwillingness or inability to engage in such talks in an empathetic manner. Certain measures could be taken by medical professionals to address and redress some of these issues:

- Appointments with people (to be) diagnosed should be approached as encounters with individuals who are knowledgeable about their condition and who actively seek solutions to better manage their health. Whereas the time for such appointments is limited, they should therefore be listened to with attention and care.

- Online platforms where people diagnosed share their experiences and insights should be consulted, as they highlight the issues people diagnosed find important, and can provide helpful indicators as to their expectations from medical encounters.
- The establishment of diagnosis and decisions about the best therapeutic approach should be arrived at in collaboration with the person diagnosed and, if s/he so prefers it, with a family member or another person who will be involved in the care process. In so doing, more attention should be paid to the realities of the life of the person, and to how they may render certain forms of treatment more acceptable than others.
- More time should be devoted to the provision of clear and detailed information about the effects and side-effects of medications that people are prescribed, to ensure that these are well understood.
- Whereas many medical professionals welcome their patients' efforts to become informed about their health, a great number thereof remain skeptical about such practices. Rather than perceiving those diagnosed who bring information acquired online to medical appointments as troublemakers or as "difficult patients", they should be recognized as individuals who try hard to improve their (mental) health. An open discussion about the benefits and disadvantages of such practices and a common selection of online platforms where the mental health-related information provided is of good quality could strengthen the relationship between people diagnosed and medical professionals. This may require, however, the creation of a new type of medical professional, someone who is knowledgeable both about mental health and about digital practices. This dissertation has shown that some very knowledgeable and skilled people diagnosed, that I have termed "online expert mediators", have managed to position themselves as mediators between people diagnosed, caregivers, and medical professionals, thereby becoming highly influential and popular online as well as offline. An alternative to creating such a new profession would be the development of closer collaborations between medical institutions and online expert mediators. This may lead to a more effective engagement with online information among people diagnosed and their caregivers, and may improve the quality of interactions between medical professionals and people diagnosed.
- Even though talk of datafication and personalization make it sometimes easy to forget, not all people diagnosed with mental conditions and their carers have access to mobile mental health applications and online resources, nor do all of them want to engage in digital practices. Medical professionals should

therefore experiment with different approaches and forms of collaboration to reach common treatment decisions together with people diagnosed, which are also based on the latter's willingness to engage with online resources. Furthermore, measures need to be taken to ensure that the nonusers of digital technologies are provided with accurate and sufficient information to adequately manage their condition.

3.4 Recommendations for policy makers

This dissertation has shown that enacting expertise on a (mental) health condition online is a complex endeavor, which is shaped by the stakeholders involved, their position and the resources they can call upon, by the architecture of the online platform used, as well as by the socio-economic and cultural climate in which such activities take place. Importantly, it has shown that expertise is a practical achievement, arrived at through negotiations among multiple stakeholders within a broader ecosystem. This has several implications for policy-makers:

- Consultations in view of the development of new policies on a given topic should be preceded by inquiries into relevant stakeholders and into the types of expertise they can each bring to the table. Simply relying on the insights provided by people endowed with credential expertise may skew the recommendations or render them less effective and useful than would otherwise be the case. The recognition of relevant stakeholders could be facilitated through the development of future scenarios and through other futuring exercises, as they can contribute to a better understanding of the effects and ramifications these policies can have upon groups that may remain invisible when only the current state of affairs is considered.
- Those entrusted with conducting the prior inquiries mentioned above should be carefully selected, as they should be sufficiently knowledgeable, open, and communicative, to recognize the substantial knowledge of stakeholders who may be lacking official accreditations.
- Attention should be paid to ensure that each stakeholder group includes individuals from different cultural backgrounds, as different values and ideals importantly shape behaviors, the use of technologies and services, as well as how certain rights are understood and made manifest.
- Such consultations should also include, from the very early stages, also representatives of the government, ethicists, legal and economic advisors, given that the effectiveness of new policies depends on the broad context in which they are deployed.

- In making public the policies arrived at through such consultations, information should also be provided about the reasons why other popular approaches were not taken up. This would enhance the democratic character of these procedures and would strengthen public trust in policy-makers.

3.5 Recommendations for governmental agencies

In my dissertation, I have argued that governmental agencies need to improve their efforts in order to effectively share information online. One of the problems identified is the rather homogeneous character which such bodies ascribe to their audiences as well as the assumption that the mere availability of information would unproblematically lead to its consumption and to desired subsequent changes in the readers' behaviors. The recommendations provided below are meant as suggestions or possible solutions for official bodies or organizations which are interested in using the internet effectively in order to share their insights:

- Online literacy workshops should be organized and provided both online and offline to ensure that people have a basic understanding of the advantages and disadvantages of using the internet, and that they are aware of their rights and obligations. While searching and sharing health-related insights online has become common practice, many people are still unaware of the multitude of ways in which their online behavior can be recorded and subsequently used for various purposes. Furthermore, they need to be made aware of how they can distinguish between claims and practices they are asked to agree to in order to gain access to an online platform, that are legal, illegal, or for which there is currently no or only incomplete legislation available. Attention should also be paid to cultural differences and to the ways in which different cultural traditions and scientific approaches may "color" the information, recommendations, and testimonies available online.
- Dedicated spaces should be created on online platforms, whereby important controversies regarding the topics discussed on these platforms are addressed and the position of different specialists and groups of experts is explained in clear, intelligible ways. While such an approach would initially require substantial efforts and may involve significant costs, it would help the public better understand the perspective of these official bodies and develop more informed opinions. At the same time, such initiatives may help broad audiences understand how to better distinguish between the social efforts through which scientific facts come into being and mere views and opinions, no matter how popular the latter may be.

- At least basic information should be provided about the development of the insights and recommendations made available on the online platform. At a minimum, the following should be included: the identity of those who author the insights made available online or, at least, the professional make-up of the group; a general description of the approach and resources used, some brief explanation on how the validity and relevance of such information is verified and updated over the years.
- Comprehensive lists of diverse online resources should be made available on specifically designated locations on the online platform, in order to increase the likelihood of readers engaging with health-related information of a certain quality. The selection and actualization of these resources could be achieved through a bottom-up approach, by conducting surveys among people diagnosed, caregivers, and medical professionals, to inquire if they use online platforms for health-related purposes, for how long, what these specific purposes are, and whether they would recommend these platforms to others, what for, and on what grounds. Subsequently a group of professionals, patients, and caregivers could be convened to develop a list of criteria by which the online platforms could be assessed. Thus, the list of online resources could consist of the online platforms most frequently mentioned in the survey which fulfill those criteria.
- Experiments should be conducted whereby information is shared in different ways and at different levels in order to increase the likelihood of readers developing an accurate understanding thereof. Next to written text, vignettes and other pictorial renditions, videos, podcasts or different audio formats would be worth providing online, as they may better respond to the ways in which individuals of different ages, with different levels of education and approaches to learning, prefer to engage with health-related information.
- Different types and amounts of information should be provided in order to address the needs, levels of interest, and familiarity of different readers. For instance, the insights shared could be structured along levels of complexity, such as basic, advanced, proficient, a division which should be clearly indicated to readers on the main page of the platform.

One of the main messages of this dissertation is that the internet cannot be used for health-related purposes unproblematically, that it cannot be a cheap replacement of the scientific, communication, medical, and care work undertaken by so many people. A lot of work is still needed for the internet to fulfill its potential as a medium actively contributing to the provision of better, faster, and cheaper (mental) healthcare. And for this we need experts: experts on the technical aspects concerning this medium, experts on algorithms, experts on the infrastructures required and their maintenance, experts on scientific communication, experts on disease and care. Hopefully some of the recommendations sketched in this Addendum may contribute to the development of new approaches and collaborations, so that this work can be furthered and (mental) health online platforms may truly benefit a great(er) number of people.

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ABOUT THE AUTHOR

After an initial study of German and English Language and Literature at the University of Bucharest, Claudia Egher (Drobeta-Turnu-Severin, 1983) went on to study Liberal Arts and Sciences (Tilburg University), which she graduated (cum laude) with a major in Social Sciences and a minor in Postcolonial Studies (Utrecht University). During her bachelor years, Claudia also followed an Honours Program and worked as academic assistant on a research project funded by the Koninklijke Nederlandse Akademie van Wetenschappen (KNAW) on the role of public intellectuals in European societies. Claudia obtained a MSc (cum laude) in Cultures of Art, Science and Technology (2013) at Maastricht University. During her PhD trajectory, Claudia was enrolled in the Netherlands Graduate School of Science, Technology and Modern Culture (WTMC). She is member of the Centre for Ethics & Politics of Emerging Technologies (EPET), of the Society for Social Studies of Science (4S), and of the European Association for the Study of Science and Technology (EASST). In 2019, Claudia briefly worked as lecturer at the KIN Center for Digital Innovation at the Vrije Universiteit Amsterdam. She currently holds an appointment as assistant professor in the same institution.