health:

Bipolar patients and creative online practices: Sharing experiences of controversial treatments

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Abstract
Bipolar disorder is among the top 10 causes of disability worldwide. It is managed through a combination of medical and psychotherapeutic interventions, but finding an effective treatment is often a long process of trial-and-error, that medical professionals and people diagnosed with this condition engage upon. This article investigates how people diagnosed with bipolar disorder enact lay expertise about the treatment of this condition online. Using De Certeau's (1988) theory of everyday practices, three tactics are identified—complexity, uncertainty, and individualization—through which people diagnosed creatively adapt medical knowledge on bipolar disorder, to render their personal experiences and views on treatment more authoritative. It is suggested that through their technological features, which allow for the accumulation and refinement of the insights contributors share, blogs may function as digital repositories of patient experiences and may thus help facilitate collective processes of knowledge production. Online data were collected from two blogs, which were selected using the Google index as relevance indicator, and were analyzed through computer-mediated discourse analysis.

Introduction

Patient engagement in mental healthcare has a long tradition, but over the last decades, several developments have led to a growing responsibilization of people in regard to their

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health (Petersen and Lupton, 1996) and have 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 self-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 precisely is meant by it, the question of exactly what patients are expected to contribute, and what the limits to such contributions are or should be remain debatable (Adams, 2011; Lupton, 2018).

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. This article therefore studies how people diagnosed with bipolar disorder (BP) use blogs to share their treatment experiences. BP affects 60 million people worldwide (World Health Organization (WHO), 2018) and remains difficult to diagnose and treat. People diagnosed with BP frequently turn to the Internet to learn from others about the nature of this condition and its treatment (Bauer et al., 2016; Murray et al., 2011). Using De Certeau's (1988) theory of creative tactics in everyday life, this article shows how people diagnosed with BP enact lay expertise by sharing their treatment experiences online in areas where the currently available medical knowledge on the effects and side-effects of medications is insufficient or controversial.

I begin by discussing how patient engagement in mental healthcare has changed over the years and the role the Internet has played in such transformations. I then introduce the main theoretical approaches this study builds upon and highlight the usefulness of the concept of tactics to analyze the online practices of people diagnosed with BP. The findings reveal that the latter enact lay expertise by creatively re-interpreting the medical notions of uncertainty, complexity, and individualization. A critical discussion of the significance of these findings is subsequently provided, followed by concluding remarks on the merits and limitations of this study.

Problematizing patient engagement

People diagnosed with mental health 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 health 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 grass-roots 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 (Lupton, 2018). 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 patients have become all the more important, as the adoption of big data analytics in healthcare and the drive toward precision medicine make highly diverse data necessary. Such data can combine traditionally "medical" markers with 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.

Theoretical approaches to patient engagement

Attempts to determine the knowledge of patients have a long history (Segall and Roberts, 1980). 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) 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" (p. 455). Epstein (1995) developed these insights, showing how some AIDS activists had "learned the language and culture of medical science" (p. 17), and were thereby able to engage in and change medical research and clinical practices. Closely related to "lay experts" is the notion of interactional expertise, which Collins et al. (2017) recently refined to denote "fluency in the spoken language associated with a practice," acquired through immersion in that field (p. 765). Anxious to safeguard the substantial character of expertise, they see interactional expertise as the property of specific individuals and groups. Despite its appeal, this concept 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 (2010), who argues that lay expertise should be

understood as "collective knowledge that may be widely available yet is still unevenly socially distributed" (p. 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. Since the design and architecture of blogs allow for the longitudinal accumulation of insights from multiple participants in the same space, they may function as digital repositories of collective experiences. Authored by one or several individuals and updated regularly, blogs comprise posts on various topics, listed typically in reverse chronological order. Blogs may help facilitate 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. They 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 and Landqvist, 2018: 1).

Lay expertise and BP

Lay expertise is often articulated in situations when scientific knowledge is lacking, when it has not yet stabilized or when the issues are too complex to be solved using only one type of knowledge (Baillergeau and Duyvendak, 2016). This makes its study in relation to BP relevant. Classified as a mood condition, BP is characterized by the alternation of depressive and manic states and marked by episode-free intervals. While its causes are not precisely known (Frey et al., 2013), BP 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 BP, therefore, diagnosed people have a significant amount of space 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. In mental health, this situation may be further exacerbated, as treatment compliance and adherence remain problematic, leading to important tensions between medical professionals and people diagnosed. The Internet may thus provide a welcoming space for people diagnosed with BP who want to share insights about their treatment experiences and thereby contribute to new knowledge.

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. Study results about treatment effectiveness are particularly likely to reach the public due

to their highly politicized character (Epstein, 2007) and to the fact that finding effective treatment is a priority for people diagnosed (Thompson et al., 2012). 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 BP 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 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 BP may be urged to educate themselves and to use online platforms in specific ways to better manage their condition. However, anthropological and science and technology studies (STS) (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.

Methodology

Tactics, in De Certeau's framework, are creative adaptations of dominant representations. Thus, I first sought to delineate the main characteristics of current medical knowledge on the treatment of BP 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 and 2016. The characteristics arrived at this way were further refined by reading the abstracts of 15 medical articles published between 2010 and 2018. The three characteristics identified are uncertainty, complexity, and individualization. They guided the analysis of the online data.

Online data were gathered from two American interactive platforms. One blog is authored by a medical professional together with a carer, whereas the other one is the personal blog of a person diagnosed with BP. The latter blogger enjoys celebrity status in this

world, as the blogs she has authored have repeatedly been listed among the top best blogs about BP 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 the following: multiple pointers to the same item, non-English blogs, blogs which had been established for less than 1 year at the moment when the selection took place (September 2014), and those which had less than 10 contributors. From these, I selected 25 entries which covered the treatment of BP, broadly understood, and which had more than 30 comments each.

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, and 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 BP, focusing on: (1) how they positioned themselves in relation to medical perspectives upon treatment, (2) how they sought to develop alternative accounts, and (3) how they negotiated the development of new assumptions 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 BP 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. Excerpts are therefore reproduced as they appeared online, with no spelling or grammar corrections.

The project that this study is part of was approved by the Ethical Review Committee of Inner-City Faculties (ERCIC), Maastricht University. The data were collected from blogs which were publicly accessible, as no fee, registration, or active consent were required for people to view them. While it was not possible to track down the online contributors to obtain permission to use the data, the insights they shared indicated that they did not expect their interactions to have a private character, and the potential harm they could incur through the publication of these materials was not deemed greater than other potential risks associated with their blog comments being publicly accessible. Furthermore, the data were not collected in real time, so that online contributors no longer satisfied with their earlier contributions would have had the opportunity to modify or remove them (as revealed by examples in the data). To further reduce the chances of risks for the online contributors, the name of the platforms was removed, the usernames were replaced by pseudonyms, and specific details about the date of the comments were not provided. While this approach does not eliminate all ethical issues, the study thus meets current ethical guidelines on online research (British Psychological Society (BPS), 2013).

Findings

Three characteristics of medical knowledge on the treatment for BP

Treatment for BP focuses on mood stabilization and maintenance and combines medications and psychotherapy. Based on the literature review undertaken (see above), I argue that current medical knowledge about the treatment of BP 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 medicine, "[t]he evidence in which different uncertainties are manifest ranges from anecdotal clinical observations to data from randomized clinical trials" (Han, 2013: 16). In the treatment of BP, uncertainty is informed by methodological issues derived from characteristics of this condition, such as the considerable heterogeneity in the definition and assessment of a mood episode, relapse (Young and Newham, 2006), and therapeutic response. There is also a lot of uncertainty regarding the mechanism of action of various drugs (Schloesser et al., 2012) and their side-effects (Correll et al., 2015). Furthermore, in clinical practice various treatment combinations are often prescribed in response to patients' needs, side-effects, or other medications they take, while there are no study results available to support them.

Complexity denotes the multiple factors which may influence the development of a disease and/or 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 hard to foresee. Complexity in the treatment of BP is derived from its diverse causes and the multiplicity of factors involved in its therapeutic approach (Andreazza and Trevor Young, 2014), which make it difficult to assess the effects of specific elements and interactions and make informed decisions about treatment. For instance, the effects of medications used in the treatment of BP are importantly shaped by one's genetic (Craddock and Sklar, 2013) and hereditary make-up, but also by one's immediate environment (Harrison et al., 2016). Complexity further stems from the number and types of medications people take (Post et al., 2010) in relation to time, such as the duration required for the effects of medicines to become manifest; or the span when they remain effective, taking into account age, or period since diagnosis (Miziou et al., 2015).

Studies on treatment response variation have generally been conducted among groups of people diagnosed with BP, but there has recently been a trend toward *individualization* (Phillips and Kupfer, 2013) as a consequence of developments in pharmacogenomics (Squassina and Pisanu, 2013) and personalized medicine (Frye et al., 2014). It is currently known, for instance, that determining a person's genotype can inform the choice of antipsychotic drugs whereas genetic, hereditary, and environmental factors may trigger different reactions in different individuals. As "an individual's unique life circumstances … influence disease susceptibility, phenotype, and response to treatment" (Ziegelstein, 2015: 888), various personal categories, many of which are dynamic and change numerous times throughout an individual's life (Naylor and Chen, 2010), have come to play a role in the development of knowledge about the treatment of BP. Evidence about treatment effectiveness has thus been expanded to include "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 BP. In what follows, I show that they do not simply take note of this state of affairs but enact lay expertise by combining different types of knowledge in order to make (better) sense of the effects and side-effects of medications.

Engaging with medical knowledge about the treatment of BP on blogs

On many online platforms, people diagnosed initiate the dialogue by sharing experiences and asking questions, whereas on blogs participants react to the posts provided by the blog author(s). This means that the online contributors studied here were constantly reminded of the current level of knowledge about the treatment of BP by the blogs' authors. The latter invoked the uncertainty, complexity, and individualization characterizing this area in their posts and often made these aspects more vivid by combining them with examples from their own practice, with their lived experiences and third-party accounts. On the blog authored by a medical professional, people diagnosed were invited to share their insights by reacting to posts about medicines used for BP, which were structured along drug families and ordered based on overall prescription frequency. On her blog, the person diagnosed took up the role of mediator between medical professionals and other people diagnosed, providing the latter with the most recent perspectives on BP treatment. On both blogs, the interaction occurred at two levels: as a dialogue initiated by the author, to which online contributors reacted directly through comments; and as a conversation initiated through the comment of an online contributor to the post and developed based on subsequent reactions to that specific comment.

The design of blogs and their affordances affected how information accumulated, and 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 are rendered easier on these blogs, as the information provided in reaction to one post can be found in a single location, even though it spans years and is provided by numerous contributors. Participation was further encouraged, as many of the posts studied remained in the readers' attention due to the platform owners having opted to mention the posts with the highest number of comments and/or with the most recent comments on the main page. It is thus possible to judge the relevance of a post years later, identify how the experience of a contributor with a specific medication evolved over time, and determine how much interactivity a post generated based on the number of comments and the time span in which they were provided.

The analysis of the online data reveals that people diagnosed are aware of current medical knowledge on the treatment of BP, as the following three tactics were identified: the mobilization of the notions of uncertainty, complexity, and individualization. Through these tactics, people diagnosed with BP reinterpret the characteristics of the current medical knowledge about the treatment of their condition in view of specific practical goals. In so doing, they enact lay expertise about treatment effectiveness. Below I elaborate on how each tactic is developed and for what goals.

Table 1. Tracking and sharing the results of self-experiments.

Name and date	Blog comment
Rachel (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.
Rachel (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.

Uncertainty. People diagnosed with BP mobilize 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 provide. They thus seek to address medical uncertainty about the effects of certain substances by engaging in self-experiments. For instance, in a post from February 2011, the blogger diagnosed with BP 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 shown in Table 1.

These excerpts illustrate how Rachel 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 Rachel 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, Rachel solves the dissonance between her findings and those of other people diagnosed by invoking the uniqueness of each person, and echoes the blogger in recommending it to others. In her second comment, experiential knowledge and medical knowledge are described as being at odds with each other, as Rachel's tentatively positive findings and intention to continue taking the pills are set against her doctor's doubts. Rachel'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

Rachel's documenting of her states reveals relatively mild improvements, her decision to continue taking NAC suggests that she may make treatment decisions using lower effectiveness standards than medical professionals. The excerpts also 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.

People diagnosed with BP also re-appropriate uncertainty about the mechanism of action of certain medications and use their personal experiences to suggest new side-effects. For instance, when discussing the effects of Cymbalta, an antidepressant, a contributor mentioned a pronounced tendency to consume alcohol. While this is not an officially recognized side-effect of this medication, people diagnosed with BP started to give more credence to this suggestion, once this experience was confirmed by many online contributors:

> Wow! I just noticed how many of you mentioned you began drinking more with Cymbalta. I started Cymbalta almost a year ago and I went from drinking MAYBE once or twice a month to drinking a LOT several days a week. I've always just thought that I lost it somehow, but now I strongly wonder if Cymbalta might have somehow affected it. My doctor switched me from Effexor to Cymbalta and I want to ask him if I can switch back. (Dylan, 2009)

Thus, the personal experiences of people diagnosed may lead to suggestions of new side-effects for particular medications through the gradual build-up of confirming testimonies. Also in this case, the experiential knowledge of many, conveyed through the accumulation of online comments, seems to make the contributor question medical knowledge, because Dylan expresses his intention to ask the doctor to reverse his decision and prescribe him again the drug he had taken before Cymbalta. This suggests that the accumulation of online testimonies which confirm side-effects that are not officially recognized may influence other people's perspective upon medications and their willingness to take them. Reframing uncertainty in terms of tactics is therefore helpful to understand how people diagnosed with BP negotiate medical knowledge to turn their personal experiences into valuable contributions. Other complex factors that can influence treatment effectiveness are discussed below.

Complexity. People diagnosed with BP mobilize the notion of complexity as they seek confirmation or additional information from others regarding particular effects they experienced, so that they can use such insights as resources to better negotiate for or against specific changes in medications with their doctor. Some online contributors re-conceptualize complexity so as to include how previous therapeutic interventions may have affected their organism's response to their current treatment. In such instances, contributors do not perceive the body and the brain as clean slates which only reveal the effects of one specific therapeutic approach. Rather, these are linked to the variety, duration, and dosage of the medicines they have previously taken:

> Sometimes you can take an anti-parkinson med like amantadine with atypical antipsychotics which usually makes shakes and tremors go away. Stimulants too can keep Akathisia at bay. For example, despite the controversy, phentermine, the pseudo-amphetamine diet med has been very effective for me in keeping away shakes, tremors, tics. It also improves my Lexapro. I

know there is a lot of bs [bullshit] about phentermine causing "serotonin syndrome" but other tests show that not to be true. For me, after 60 some meds—phentermine made those horrible shakes disappear, controlled the weight gain associated with atypicals, and has a very good antidepressant value as well. There's just no "money" in testing or using this med, but many psychiatrists have experience with it. Hope this helps. As for TD [Tardive dyskinesia], it is often reversible or decreases over time. Depends on how much A-pscyh you took and for how long. (William, 2009)

William's comment reveals the complex combination of drugs that people with BP need to experiment with to address both the symptoms of their condition and the side-effects triggered by some medications. William suggests that positive results can be obtained using other classes of medicines than those specifically developed for this condition, depending on one's medical history. Whereas personal accounts are generally at the bottom of the hierarchy of evidence currently dominant in medicine, William challenges it by considering his experiences sufficient for an initial confirmation of the effectiveness of medicines which have not been tested for the treatment of BP because of low financial incentives. To render his claim more convincing, he draws upon different types of knowledge, as he combines the description of his embodied experiences with medical terminology and also invokes clinical practice. Thus, such online contributors re-appropriate complexity to suggest avenues about treatment effectiveness they consider of limited interest for researchers.

Other contributors re-appropriated complexity about the effectiveness of treatment to argue against the use of generics, as shown in Table 2.

Table 2 reveals that online contributors approach generics based on knowledge and practices they have previously developed using brand medications. Thus, they try multiple types of generics to find effective ones and advise others on how to identify them. Via practices of "tinkering," they also combine the generic with other medications in the hope of satisfactory compounded effects. Thus, people diagnosed with BP enact lay expertise by taking up the role of investigators, as they try to make sense of their experiences with generics by searching, comparing, and seeking to understand different types of information. To do this, they bring into relationship the onset and severity of certain symptoms with the use of the generic and its manufacturer and they make comparisons between their states at different moments in time. Furthermore, they show that the risk of generics being ineffective is not only restricted to particular mental and physical states, but may affect aspects of their lives that are very important and meaningful to them. From this point of view, the blogs seem to serve as spaces for social learning and consultation, as online contributors not only confirm the (in)effectiveness of (certain) generics one of them initially described, but they also share information acquired from doctors or pharmacists.

The exchange between Kendall and Richard shows how the former's observations are confirmed whereas her doctor's claims are challenged through Richard's description of his doctor's views. The adverb "really" and the punctuation signs at the beginning of his comment convey the disbelief he experiences upon reading about Kendall's doctor's perspective on generics, while the suggestion that "she hasn't gotten that memo yet" casts doubt about how knowledgeable and up-to-date she is. To give further credence to

Table 2. Some exchanges on the difference in effectiveness between Lamictal and generics.

Name and date	Reaction to blog post	Reaction to specific comment
Kendall (2009)	I've been on Lamictal for 8 years and it has been a godsend, successfully treating my bipolar disorder and allowing me to be a productive entrepreneur and author. HOWEVER my insurance company recently switched me to the generic brand and I am suffering. I had the first depressive episode in many many years and I feel like I'm spiraling out of control. My doctor won't listen to me, she says that the two medications are identical. I'd believe her if I didn't feel this way. I'm going to pursue this further … hoping to get it resolved before something terrible happens.	Really?! My doc said no way to even letting me get on the generic. Something about the fillers they are putting in it being really strange and inconsistent. She said it is screwing with a lot of patients. Maybe your doc hasn't gotten that memo yet. Stick with the real stuff and be well! (Richard, 2013)
Carson (2010)	I have read the comments here and find many who have concerns with taking generic. The concerns may be legitimate. From the studies I have read, generic for psych meds is not the same as for non-brain type meds. The fillers used in lamotrigine, for example, may affect the transport in the brain and therefore, for some people, may not be effective. I am not a physician, but, speak from study/experience.	
Nick (2015)	By the way—I have noticed BIG differences from lamotrigine (generic) between the two manufacturers my pharmacy uses. I won't take the one at all. The one that is best, for me, if labeled "CADI."	I've experienced horrible generic variations too & have found TEVA to be the only mfg consistent for me. My psych has had to specify this on each Rx to make sure this is the brand I receive. (Greg, 2017)
Nicole (2017)	I'm not sure what is going on with me. I take max dose of Lamictal and I thought everything was fine. When I say fine I mean not going from 0 to 60 in a second with my anger. I started running low and couldn't see my Doc for another three weeks. I started taking half dose then ran out for a day. Finally was given enough from statcare to get me through till I see the Doc. Ever since then which had been a month now I am back to yelling at the top of my lungs and not being able to control my thoughts or feelings. I want to lash out and be mean when I do it. I'm going to lose my marriage. I'm 50 raising two of his grandkids that are a hot mess themselves. I go off on them and I am destroying our family. Could it be that the Meds are not fully back in my system? Is it just life!	Nicole, I have been on generic lamotrigine for several years now. I take it with bupropion and together they have helped (not fully but much better) my symptoms. However, my pharmacy changed the manufacturer of the drug on me and all of a sudden I went back to the full blown bad symptoms. I asked the pharmacy (Safeway) to get me back on the previous version and they did it for several months and all was well. Then, they changed it again and then said the corporate office said they could no longer offer anything but the new one. I moved my prescription to another pharmacy and they put me on yet a different "brand" and it has worked very well, may be a bit better than the original one I was on. […] I found out that the FDA has approved 10 or 11 different brands of the same drug from different manufacturers. In my opinion they are not the same. You might try changing the brand you are using. (Nicholas, 2017)

the idea that generics are less effective than brand medications, Richard uses several markers of evaluation, contrasting the "really strange and inconsistent" fillers of generics with "the real stuff" brand medications are supposed to represent. Table 2 also reveals the lack of agency people diagnosed with BP experience in regard to treatment decisions, as important institutions "switch" or "put" them on different medications, while some doctors "won't listen." Whereas Kendall's comment illustrates the loss of voice she experiences in her interactions with her doctor, the fact that her experiences are ratified online by others suggests that blogs may become important spaces for people diagnosed to reclaim agency and to strengthen the epistemic authority of their claims.

As shown in Table 2, blogs can facilitate the accumulation of insights over time. While in some cases the comments were provided in close proximity to each other, in a temporal succession or as reactions to specific comments, in other cases, the readers had to be more active and track them themselves. Thus, whereas the idea that generics had different effects than Lamictal was put forward in September 2009, it continued to gather comments until 2017. This demonstrates that this view remained relevant. It also indicates that people expect contributors from previous years to monitor that post or to be receiving notifications when a new comment is provided.

Reframing complexity in terms of tactics highlights how people diagnosed with BP render the space of medical knowledge more "habitable" by expanding it and adapting it to their own experiences and views on treatment. They thus indicate that they believe a more diverse array of chemical interactions and practices to be influencing treatment effectiveness. Personal preferences also inform the choice of therapeutic intervention, and they are discussed below.

Individualization. People diagnosed with BP creatively engage with medical insights about individualization in treatment response to indicate that diverse personal preferences and circumstances may be 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, whereas online contributors interpret individualization so that each person's health and illness trajectory becomes unique. For instance, people diagnosed with BP argue against evidence derived from randomized controlled trials 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" (John, 2014). Other contributors believe medications to have an individualized effect upon each person taking it: "So, is it [Cymbalta] a good drug? It is for me!" (Marianne, 2009). Such individualizing effects are emphasized through the frequent use of emotional and affective markers to explain their impact upon the contributors' lives. For instance, 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. 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 personal experiences in a field where authoritative knowledge is 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 the medicines. In so doing, it becomes apparent that they use different standards to determine treatment effectiveness, as they focus on whether their health allows them to perform their duties or engage in activities they enjoy:

> When I was on Seroquel regularly it kept my mood stable, but kept me from losing any weight (no matter how hard I tried), dulled my responses to others (especially in interactions with my toddler and husband) and made me constantly tired. My memory was like Swiss cheese. I couldn't even read the notes I would take to try to remember what my colleagues were telling me at work. I absolutely refuse to go back on it. (Violet, 2009)

Such an account succeeds in rendering the effects of specific treatments thick, meaningful, and understandable to people diagnosed as well as undiagnosed. It ties treatment experiences to a person's multiple functions and social roles. Others can assess the effectiveness of this specific treatment by considering how their life circumstances match those of the contributor. While studies are underway to determine the therapeutic effects online interactions in support groups might have upon participants, some online contributors suggest that reading about the experiences of other people diagnosed online can have a therapeutic effect: "this blog and your collective experiences have been better for me than any medications as they usually have side-effects that are not welcomed" (Billie, 24 March 2014). They thus expand the meaning of treatment to a great variety of practices which have beneficial effects for some individuals.

Online contributors interpret individualization in treatment response so as to also entail specific personality traits and personal needs. Some comments highlight that characteristics such as risk aversion or tolerance, and curiosity play an important role in the treatment approaches people diagnosed try. Others reveal that people diagnosed evaluate treatment effectiveness based on the extent to which it allows them to live life according to personal values and preferences:

> While I can understand from the three or four times I've been on it [Lithium] that it can work, I simply couldn't tolerate the emotional detachment from people it engendered. It was like living in a fishbowl, where I could see out and people could see in at me, but there was a layer of glass between us and no possibility of connection. I had some weight gain and fuzzy thinking, the tremors and having to run to the bathroom, but they got better with time and dosage adjustment. But the detachment always was there. (Joyce, 2008)

Thus, online contributors mobilize individualization to provide insights meant to enable other people with BP 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 BP render the space of medical knowledge about treatment meaningful to them by inscribing in it elements of leisure and experience they find fulfilling. The implications of these findings are discussed below.

Discussion

This study has shown that by re-appropriating medical perspectives and combining them with personal insights, people diagnosed with BP enact lay expertise by sharing their experiences about the effects and side-effects of medications online. Through their exchanges, online contributors acquire insights necessary to achieve individual goals, such as finding medicines to better manage BP while also engaging in activities they value, or becoming sufficiently educated so as to gain more agency in regard to their choice of treatment in their interactions with medical professionals. Blogs thus function as spaces where people diagnosed are encouraged to document and reflect upon their own treatment experiences, and, in so doing, they render visible the multitude of ways in which treatment effectiveness can be understood, and the individual variations and preferences regarding the symptoms medications should help manage. 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, blogs may serve as spaces for consultation and social learning about treatment effectiveness. These findings are in line with previous studies which 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 article has shown that people diagnosed with BP can enact lay expertise and thereby contribute to the production of knowledge even through 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). The findings presented here have shown that when combined with the awareness of medical uncertainty, the cultivation of such pro-active behaviors 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 insights 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).

The accounts discussed here reveal that the very sharing of personal experiences shapes not only how treatment effectiveness is assessed but also how different types of evidence and knowledge are 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 BP revealed their appreciation for insights acquired through the accumulation of personal testimonies, 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. While at this point this is merely a conjecture, it is in line with the findings of Mazanderani et al. (2013), 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" (p. 420).

Limitations

The type of data used in this article does not allow for any conclusions regarding the impact that the accumulation of confirming testimonies has upon people's actual treatment practices and their interactions with medical professionals. Further research with users and contributors is therefore needed to understand how the use of blogs influences their treatment-related attitudes and practices. Another limitation of this study is that it is based on data from blogs authored by people who enjoy substantial authority, either through their medical credentials or through their high standing among people diagnosed with BP. While their popularity had an impact upon the number of readers and contributors, studies focusing on different types of blogs are needed to acquire a more detailed understanding of how blog authors influence the content of the reactions received. Since this study is based on posts with many comments, the insights provided may be more representative of people's experiences with certain therapeutic approaches than others. It is also shaped by the politics of the search engine's algorithm, which influenced the blog selection through their ranking in the initial query results. Furthermore, since the findings are based on the experiences of readers who were motivated enough to contribute online, they do not represent all people diagnosed with BP. More studies are needed to understand the perspectives of people who use blogs 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.

Conclusion

People diagnosed with mental health conditions have actively engaged with 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 has provided 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 BP 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. By enacting lay expertise, they thus sought to render the space of their interactions with medical professionals and of daily life with BP more comfortable.

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