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La construction symbolique du concept de patient dans l'ère de la datafication

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Résumé: Avec le développement des nouveaux médias, toute une série d'entités théoriques que nous considérons généralement bien établies se sont révélées d'une perméabilité particulière. Le philosophe Michel Foucault a mis en doute les certitudes du public sur le concept de maladie mentale et a alimenté des décennies de débat sur le relativisme et ses effets. Les idées de Foucault se révèlent encore plus précieuses aujourd'hui, car les nouveaux médias ont poussé les choses plus loin que nous n'aurions pu le supposer il y a quatre décennies. De nombreuses personnes établissent leur propre diagnostic en suivant les sources du Web, en achetant leurs médicaments en ligne et en décidant le moment où ils doivent arrêter le traitement. Il y a sur Internet des tribus favorables ou opposées à la vaccination, à l'utilisation d'un médicament ou à une procédure médicale. La plupart du temps, ces tribus mènent une lutte lointaine, mais cette lutte a finalement un impact concret sur la vie des individus et des communautés. Mon article analyse, à partir de quelques cas concrets, la manière dont le concept de patient est réinterprété et redéfini à travers du contenu publié sur les sites Web roumains dans le domaine médical. Si, jusqu'à récemment, nous recherchions les contours du patient et ses comportements dans les encyclopédies médicales officielles, ces limites ont aujourd'hui perdu de leur cohérence et une grande partie du public construit une image de ce que signifie être patient en suivant le flux d'informations diffusé sur les sites. Il est presque inutile d'ajouter que le public est souvent appelé à traiter des informations contradictoires.

Abstract: With the development of new media, a whole series of theoretical entities that we generally consider well established have proved particularly permeable. The philosopher Michel Foucault questioned the public's certainty about the concept of mental illness and has fuelled decades of debate about relativism and its effects. Foucault's ideas are even more valuable today because new media have pushed things further than we could have supposed four decades ago. Many people make their own diagnosis by following the Web's sources, buying their medications online and deciding when to stop treatment. There are tribes on the Internet that are favorable or opposed to vaccination, the use of a drug or a medical procedure. Most of the time these tribes fight a distant battle, but this struggle ultimately has a concrete impact on the lives of individuals and communities. My article analyses, from a few concrete cases, how the concept of patient is reinterpreted and redefined through content published on Romanian websites in the medical field. Although, until recently, we have been researching the contours of the patient and his behavior in official medical encyclopaedias, these limits have now lost their coherence and a large part of the public constructs a picture of what it means to be patient by following the flow of information disseminated on the sites. It is almost pointless to add that the public is often called upon to handle conflicting information.

Keywords: patient, datafication, E-health, medical humanities

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Mots-clefs :

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SOMMAIRE

Introduction

New media have shaped almost every important sector of our lives, from commerce to interpersonal relationships. Even if medicine seemed to be a resistant area, digital technologies already changed the way of practicing it, from the increasing use of devices and screens to new techniques such as the gene editing. The relationships between doctor and patient are many times mediated by digital technologies that are very sophisticated and sometimes they supersede the traditional way of practicing medicine. Borrowing the term “creative destruction” from Joseph Schumpeter, Eric Topol announced “the creative destruction of medicine, of how medicine will inevitably be Schumpetered in the coming years”[1]. The significant transformations that accompany a radical innovation such as the digitizing of human being (determining the complete map of the genome) are the consequence of an “unprecedent super-convergence. It would not be possible were it not for the maturation of the digital world technologies - ubiquity of smart phones, bandwidth, pervasive connectivity, and social networking. Beyond this, the perfect digital storm includes immense, seemingly unlimited computing power via cloud server farms, remarkable biosensors, genome sequencing, imaging capabilities, and formidable health information systems"[2].

The remote care delivery or the telemedicine, the use of software for health care or the health informatics, or the use of artificial intelligence in medicine are just a few examples of the broad and complex conjunction of new media and the medical domain. E-health is a very large term which refers to the use of digital means in order to provide and deliver information and resources related to health. E-health relegates to many concepts, such as:

"• Electronic health records.

- Mobile health or m-health (e.g., apps, wearable technologies, medical devices).

- Telehealth or telemedicine (e.g., whereby a patient can consult a health-care worker on the computer, a tablet, or a phone).

- Health-related e-learning (use of technology and media for training and educating both a broader audience and the health workforce).

- Social media for health (informal, social online communication channels).

- Health data analysis and "big data" (transformation of data to provide insights and evidence for decision- and policymaking)"[3].

New approaches in diagnosis, therapy and prevention are now possible not only by analyzing big data from a diverse population, by also by individual and personalized data, collected through various means (biological, clinical, imagistic). Thus, the rule of "4 P" medicine: predictive, preventive, personalized, and participatory seems to be applicable nowadays.

The participatory culture or the do-it-yourself style has influenced the people in order to put in the question the renowned authority of the doctor. Thus, "homo digitus" searches medical information, compares them and finds alternatives. Many people diagnose themselves, use homeopathies or natural remedies, and avoid specialized consultations. The issue of vaccination, for instance, showed clearly that the medical authorities are not only challenged but many times rejected because people do not have enough confidence anymore and perceive them as being insufficiently informed. This situation represents an overturn, an inversion of positions: before social media, the doctors had the epistemic authority in front of their patients, while now this authority is many times questioned or even contested. In Romania, non-medics have become principal actors in the debates against vaccination, with consistent support from the parents. Thus, a situation that until now did not raise any issues has produced recently a lot of discursive flame; also, the medical arguments were seen as a kind of arguments among others, with no special level of persuasion.

The online platforms (blogs, sites, forums) are heavily used, and some of them are managed by medical staff. Not only the patients were empowered by new media opportunities, but also the doctors use the online facilities in order to communicate medical advice. Even if the quality of health information could be lower, social media (SM) represents

> “a complementary channel of information to other official means for the health data collection such as the epidemiological surveillance activities and control carried out by health authorities. In recent years it is possible to find a lot of examples that show many applications of the analysis of SM for health purposes such as disease surveillance, health promotion, and public health or a parallel source to the official means of pharmacovigilance, as a way to discover new drug side effects associations not described before or new applications for old drugs. Several conditions and diseases can be monitored on SM platforms, identifying patterns of behavior that give clues about the personality profile, mental health, and the possibility of success in smoking cessation or eating habits of their users”[4].

Moreover, the number of entities involved in a medical act is growing: “non-medical” actors, such as companies, are today deeply involved. Digital brands like Apple, Google or Facebook are now “health players” that provide but also collect medical resources and data. The pharmaceutical industry represents another pillar of medicine. Mass media, mainly through advertising – orientate the public towards specific medicaments, medical services, or health care providers. We witness invented pathologies with consequently advertised drugs and solutions; also different fashions or social trends imbue the medical consumption.

In the hyper-consumption society, as Lipovetsky[5] coined it, *homo consumericus* is turning into *homo sanitas* that frenetically consumes medical products and services (consultations, remedies, articles, online medical information). He is medicalizing its behaviours by eating obsessively correct, doing sport, eliminating tobacco and consuming many products just to grow his immune system. We have smart watches that measure the blood pressure, burned calories or the number of steps. The hypermodern human being is constantly preoccupied with his health maintenance, but, as Lipovetsky observed, he is also susceptible to hypochondria. In the same time, this category of people is accompanied by the people who rarely are caring for their health (and in this context, the socio-economic and educational factors are the most important).

1. Digital medical humanities and datafication of health

The spectacular development of specific fitness and health apps, together with the growth of online discussions about health issues (online consultations, diagnosis, advice) leave behind a lot of digital fingertips and a large amount of information. The majority of apps and platforms request many data (personal, clinical info) that is automatically aggregated, stocked up and analysed in order to inform a variety of stakeholders. In this vein, the problem of the property of these data is still acute, even if The General Data Protection Regulation (GDPR) is active from 25 May 2018. Thus, as Arthur André formulated, “Who will manage these new data generated? Who will analyze them and make them intelligible in the medical sense? Is it the citizen himself? Is it the State? Is this a new private actor of the system, having enough technological advance, like the American GAFAMI (Google, Apple, Facebook, Amazon, Microsoft, IBM) or Chinese BATX (Baidu, Alibaba, Tencent, Xiaomi)?”[6]

J. Van Dijck and T. Poell observed the double logic and rhetoric used in the presentation of health apps: on the one hand, is the promise of precise and personalized solutions to medical or lifestyle problems; on the other hand, is the call for contributing to the public good (by contributing to research and public education). Thus, “it often remains unclear whom gets served by data-based platforms: individuals, communities, private industries, researchers, or society as such. The dual claims are often articulated in a diffuse rhetoric, where terms such as ‘sharing’, ‘open’, ‘transparency’, and ‘reuse’ seem to be ambiguous, thus propelling different agendas”[7]. Two mechanisms are essential for digital platforms, with debatable effects: *datafication* and *commodification*.

The first concept refers to the transformation into data of every aspect, from pulse, test results, symptoms or personal measurements to subjective experiences or comments. Data can be generated by devices or by users’ activities such as posting different health-related comments. Big Datasets conducted to the elaboration of distinct “omics” methodologies such as epigenomics, proteomics or metabolomics that are now used. Big Data require an intensive interdisciplinary approach and their existence is not translated automatically in useful things for people. Thus, we have to emphasise that they have to be cleaned, stored, curated, visualised until sites such as HealthMap.org could be launched for the public health surveillance. Also, they confronted with different kind of issues: technical issues and also ethical and legal problems[8]. The first category includes the quality, reliability and completeness of information, and also security related issues, that are very important in order to preserve privacy. The second category is a sensitive one, because “unprofessional uses of SM are not uncommon and diverse improper behaviors such as posting sexually suggestive photos or criticism of others, diverse violations of patient privacy, are among the most common unprofessional behaviors detected in these platforms”[9]. As Charles Ornstein[10] correctly observed, health professionals and services are today rated in the same manner that we rate hotels or restaurants, using specific sites and writing reviews. Even these practices prove to be a part of the democratization of healthcare by giving voice to patients, we have to admit that they also have a “dark side”. Thus, in responses to negative reviews, many private information have been disclosed without permission and consequently many rules and policies have been violated.

The second concept – commodification – refers to the transformation of data in money. When information turns into valuable goods by means of advertisements, for instance using free apps in exchange for personal data, we can talk about monetization of data. The possibilities of combining health data with any other kind of information alongside the automated collection of them represent just a quick profile of the power of new media in this sector. "The datafied power", as Ruckenstein and Schüll[11] noted, originates from the divide between "data poor" (citizen that offers information) and "data rich" (institutions that collect and mine this information). Data can be obtained through promotional gifts, by extraction from data subjects or even hijacked. But, from another perspective, if doctors do not have data in emergency situations, the subjects are also vulnerable.

Olivia Banner talked about "communicative biocapitalism" in order to depict the new markets and industries that emerged from "the value generated out of the online voice of the patient"[12]. With this concept, Banner resonates with Dean's term "communicative capitalism"[13] in order to point out the existence of a new form of capitalism that incorporates biomedical, technologic and scientific developments made since the late twentieth-century. Thus, "communicative biocapitalism is an economic logic powered by the integration of people's articulations of their somatic experiences into biomedical research and modern health care, and a key platform for this integration is patient-networking websites"[14]. In this context, Osther's call – "it's time for digital medical humanities"[15] - is very meaningful. Big data require an in-depth analysis that has to be done with digital humanities methods. In this respect, the already established collaboration between computer scientists and digital humanists has to continue in order to properly understand the patient and his or her experiences through big health data. In this complex equation, medical humanists are also needed.

The big and multifarious narratives that patients produce could be interpreted in the same way that digital humanists interpret their corpora today: through *distant reading*. It is, indubitably, an interesting and debatable method that requires a lot of skills but it also could bring to the surface significant patterns. Also, narrative medicine became a discipline studied in universities (Columbia University[16] being an example in this case). This is an interdisciplinary area, with anthropological, philosophical, literary and storytelling insights and many researchers in this field are, in fact PhDs in Literature. Through close and distant reading, subsequent perspectives, methods and ethics, humanities add value to medical education and practice. In combination with new media, those foster so many new tools of research, study, simulation or visualization[17]. Medical humanities[18] could produce meaningful results in order to re-connect with the patients in terms of human beings, to better communicate and understand them. Narrative medicine intends to develop the narrative competence in clinicians, as receivers and interpreters of different stories about illness and health. Thus, reflective writing, deep listening to others, attention focused on someone are used in practice because “there are clinical implications to these activities, for the capacities that are developed in this work can be employed at the bedside with patients to allow deep listening, nuanced appreciation of stories, and witnessing another’s experience. For the patient, the application of these capacities may bring about a sense of being seen and the possibility of alleviating suffering”[19]. In practice, the narratives work in a theatrical-like way: the scene of narration is constituted by the patient - physician relationship; the content is the patient’ anamnesis and story, while the doctor has to listen and respond to it (by creating another narrative). The narrative knowledge represents an important acquisition, “including the narrative structures implicit in Aristotle’s conception of *phronesis*, or ‘practical reasoning’, and in Charles Sandres Peirce’s conception of *abduction*, or ‘the logic of discovery’”[20]. Alongside medical education, Schleifer and Vannatta consider that other *technē* could improve the medical process in obtaining *eudaimonia* seen as the “well-being of health”. For them, *phronesis* should be a systematic knowledge taught to medical students, with storytelling skills and ethics. The logic of narrative is closely related not only to *phronesis*, but also to “the logic of diagnosis, particularly in relation to the conception of abduction that Charles Sanders Peirce developed in the early twentieth century, insofar as abduction offers a working-out, often resulting in a narrative, of Aristotle’s ‘practical syllogism’”[21]. In this respect, the integration of the narrative abilities and of the medical humanities into medical education and practice becomes “the chief concern of medicine”. In sum, medical humanities could shape the identity of doctors who could form a medical type of culture that could be more “humane”.

As Alan Bleakley pointed out, the medical humanities are in a process of transition from the “first wave” (enthusiastic, uncritical and little reflexive) to the “second wave” (more critical). Even if exaggerated on purpose to better comprehend the message, as Bleakley noticed, “examples of this uncritical first wave can be seen time after time as medical schools advertise their medical humanities wares with great gusto and pride, for this to be an elective programme attracting few students who write some (often bad) poetry or make some music as a diversion from core studies”[22]. The later is centered on critical educational intervention, critical engagement and potential transformation. Anyhow, there are some risks in the distancing from the clinical practice and in not optimally integrating the humanities in the medical education. Also, different levels of resistance are felt when medical humanities are proposed as a part of curriculum, the major claim remaining the measurement of their impact or efficacy. In the same time, Bleakley strongly sustains the value of the medical humanities that “are no longer supplementary or complementary but actively reformulate what clinical thinking and clinical practice – or the clinical imagination – might be. The arts and humanities are given a central role (i) politically – in democratizing medicine, where they also educate for tolerance of ambiguity, and (ii) aesthetically – in providing the necessary media for learning how to communicate professionally and sensitively through a moral imagination and learning how to engage close noticing in physical examination and diagnoses”[23].

2. The manifold spectres of patient

The various changes recorded in how medicine functions today, at the level of education or curricula and regarding new kind of convergence offered by the new technologies put the concept of patient in a new light. The datafication of medical domain may transform the patient in a sum of information that have to be interpreted by distant reading. In the same time, the democratisation of medicine and the huge online medical stories seem to give a new voice to the patient. Beside the classical studies that investigate the ill and medicalized body, the E-health brings new ways in which the patient is symbolically constructed and perceived. I will point out some categories that epitomize the contemporary “parameters” in which the concept of patient could be understood.

Participatory patient

In new media times, people are participatory users that generate content and become more exigent with everything that happens. We are living in a more participatory model of culture, “one which sees the public not as simply consumers of preconstructed messages but as people who are shaping, sharing, reframing, and remixing media content in ways which might not have been previously imagined. And they are doing so not as isolated individuals but within larger communities and networks”[24]. In 1992, Henry Jenkins coined the term “participatory culture”[25] precisely to depict the potential of the new environment in changing social interaction and even the traditional power roles. The consequences of this phenomenon are traceable also in the medical domain.

Patients are participants in the medical act, even if they do not have equal roles with other participants (doctors, pharmaceutical companies). At the same time, researches speak about the democratized medicine, in which patients collaborate with medics in order to straighten out, preserve or improve their medical condition. As medical area intersected the digital, the patients were enhanced with many possibilities to inform themselves, search for alternative treatments or doctors, challenge the diagnosis, self-diagnose or contribute on social media by posting medical content and experiences or by reviewing medical staff or services. New media created the scene for a new actor: the voice of the patient. As Olivia Banner noticed, “stitched out of the threads of neoliberalism, healthism, and biomedicalization, the technological assemblage of digital health is sutured to one fundamental figure: the voice of the patient. Without the voice of the patient at its center, digital health would take an entirely different form, if it could exist at all”[26]. These liberating times come together with a plethora of risks: the lack of competencies in order to select the relevant medical information, the emotional overbid and the self-medication are just a few. From another perspective, social media raised the curtain from sensitive topics: the conditions in hospitals, the lack of important medicaments, the poor competencies of some doctors. In Romania, just to exemplify, the Colectiv case revealed major lacks in medical services for burned patients. Also, the online donations for intricate diseases that necessitate expensive treatments, many times abroad, represent another example for the power of people united through digital media.

Patient as information donor

When people offer medical data for multiple apps and platforms, they become numbers in a possible future statistic. They also become abstracted from time and social space, but extremely open, giving access to previously inaccessible zones of their intimate lives. Digital tools and software exemplify the medical gaze and reinforce Foucault’s ideas of surveillance society and biopolitics or Deleuze’s society of control. The *digitized patient* has digital prosthesis like apps that monitor their bodies. Collecting medical data could lead to an increasing mode of power that seeks to control important information of the population. People feel more powerful and in control because they could find themselves some information that only doctors gave them traditionally (as blood pressure or pulse), but to the same extent they are information donors that could be use in different modalities. Self-tracking can offer sufficient material for experiencing ourselves; in Western philosophical tradition, the body was most of the time occulted, ignored, or even despised. Clinical or physiological sets of data arranged in various visualisation modalities could trigger questions, reflections and self-narratives about corporeality. Moreover, the body itself becomes present and some of its mysterious functionality is revealed. Thus, a double logic is simultaneous at work: for the patient, the recordings of his or her vital characteristics represent an actualisation of the body, a kind of presentification, while for those who collect these data the patient is an abstract entity whose information can be joined with others in forming a wider perspective. Self-tracking can also adjust (sometimes with negative effects) the power balance between doctor and patient and can intermediate between medical protocols or diagnostics and subjective experiences of body, health and illness. In some chronic diseases, the patient has to self-monitor his or her condition, becoming a real ally of the medical staff. Thus, the remote access to previously hidden or private medical data could lead to *tricked patients* but also to *informed patients*. The ethnographers that investigated this situation found an ambivalent relationship with self-tracking: “there is a curious resonance between this vision of empowered, resisting individuals that many ethnographers of self-tracking celebrate and the rhetoric of consumer empowerment found in discourse of digital health”[27]. People want to take control and become responsible for their own bodies, but they also wish to delegate that task. Also, social media and medical forums and virtual communities became favourite “places” were people write about their medical experiences or review hospitals or doctors. By doing these activities, they also let behind a lot of information, some of them very personal or intimate. The border between public and private is constantly challenged, and the subjective and emotional architecture of social media could produce a bias in this respect.

Patient as reflexive consumer

This is not a new category, specific only for contemporary age, but its characteristics are accentuated today. The origins of consumerism in health sector are closely tied to the social movements of the 1960s and 1970s. Challenging the authority of experts and making informed choices for your own body are at the core of this stream. As Sulik and Eich-Krohm stated, “American society has created a healthcare market where people see themselves first as consumers, and then as patients”[28]. So, patients were a kind of consumers and until now, but what is interesting nowadays is the fact that they are named directly consumers, sometimes instead of patients. The term patient has been gradually replaced in the medical field by the term consumer; people buy health plans or services made by specialized medical professionals and they can choose between private and public clinics or labs. But these activities are not the only ones that introduced the concept of consumer in the medical vocabulary. It is also the reason of diminishing the psychological heaviness of being labelled as a sick person. Also, the consumer society *per se* has imposed its logic in many others sectors; the development of medical programmes for prevention or health monitoring contributed to the intrusion of the economic ways in the symbolic construction of the patient. Advertising is consumer-oriented, even if its content is represented by medical products; its influence is well-known. Another major factor is represented by over-the-counter drugs that opened the path for auto-medication. In this context, people are rather buyers or consumers rather than patients; there is no authority that could categorise them as patients, only their own decision of treatment.

The digital economy created the phenomenon of *prosumption*, in which the virtual patients consume medical content and also contribute to this large collective intelligence. Thus, patients do not consume only medicaments, but also they consume information. In this respect, Lupton[29] talked about *the digitally engaged patient* that described its active role in consuming and producing information about health issues by using digital media. The patient empowerment could create an ideal *patient-citizen* that is responsible for managing his or her medical condition and by doing what he or she helps the healthcare system. At the same time, this online exposure could lead to a *commodified patient*, when his data are monetized. This emergent economy oscillates between the valorising of sharing and the novel ways in which data could be exploited.

In correlation with “reflexive consumerism” and transparency in healthcare, researchers as Adams[30] talked about a *reflexive patient*. The theories developed by Giddens are here at work, implying that the patient is characterized by individualization and self-reflexive discourses that lead to action. People are actively involved in managing their health, exerting their rights to compare options and to choose. Nevertheless, “this translation of theories of reflexive consumerism to actual patients in practice, however, is problematic. The rhetoric of policy and website promotion assumes easy-to-define customers with calculable preferences and overestimates the roles that information, and the internet as a coordination and distribution channel, can play”[31]. Also, the (self) empowerment of patient comes with an increasing part of responsibility of his or her medical options.

3. A brief example

I was interested to observe how medical sites communicate with their target audience, how they construct and label the public and what terms are used for this goal. Are they designated patients, consumers, human beings? Even if forums or virtual communities dedicated to medical topics would have been most productive “places” for research, I think that the section “About us” condensates the perspective of medical service providers on their public and also on their virtual relationship. I selected 12 websites of Romanian hospitals and clinics – 6 private and 6 public/state institutions. Thus, the succinct analysis of their presentation represents an inverse path: if the major part of literature emphasised the patient’s perspectives on his or her role in the medical act today, I try to see how medical institutions perceive and name their public. My aim was to simply identify the terms used in their online descriptions. Thus, 7 medical institutions address their public with the traditional term “patients”; also, 3 from these 7 cases have chosen to use together with the concept of “patients” the terms “human beings”, “people”, “persons”, “our peers”, “the person who suffers”, “the ill persons”. Also, for three sites, the term “patient” comes after the use of “human beings”. One site avoided the direct form of addressing, but the general idea of consumer could be found in formulations such as “we invite you to test the quality of our medical services”. Also, one description (for a private clinic) used only the term “ill people”, and another one (a state hospital from Bucharest) used the expression “residents from Bucharest and neighbouring counties”.

Four sites use only the term “patients” in their websites pages dedicated to their description (section “About us”); curiously, 2 are private and 2 are state institutions. Overall, the state clinics use mostly a traditional vocabulary (“patient”, “ill people”, “the persons”), while private clinics use more synonyms and sometimes hesitate among several expressions.

Of course, this brief look does not have the claims of a representative research with generalizable conclusions, but it functions only as an example of how medical institutions “talk” online and depict their public. An in-depth analysis, with a representative sample, will decipher more about this issue. Nevertheless, only a few part of the sites visited are user-friendly, from the multimedia requirements related to usability to content demands (this situation was also found in the case of 2 sites of private clinics, where their main goal is to sale medical services).

Conclusions

Although, until recently, we have been researching the contours of the patient and his behaviour in official medical encyclopaedias, these limits have now lost their coherence and a large part of the public constructs a picture of what it means to be patient by following the flow of information disseminated on the sites. New media technologies bring a lot of possibilities in order to be more informed, to have more options, to speak loud about problems or to review doctors or clinics. Virtual communities that support people in suffering or donate for better treatments are examples of inclusion and care. But, as we know, when something is won, something else is lost, and researchers warn about new roles that patients play today, such as information donors or commodified people. The traditional power relationships are interrogated today and, in many circumstances, they are sensibly modified. The "profile" of patient became diversified and complex; doctors and clinics must cope with these changes and with the pressure of finding better ways to communicate together with the best medical services. An integrative image about the present situation requires the contributions of humanities, digital literacy and interdisciplinary methods.

References

Adams, Samantha A., "Sourcing the crowd for health services improvement: The reflexive patient and 'share-your-experience' websites", *Social Science & Medicine*, 72(7), 2011, pp. 1069-1076.

André, Arthur, "Future Trends for Our Health-Care System", in Arthur André (Editor), *Digital Medicine*, Cham, Springer, 2019, pp. 103-106.

André, Arthur, "The Information Technology Revolution in Health Care", in Arthur André (Editor), *Digital Medicine*, Cham, Springer, 2019, pp. 1-7.

Banner, Olivia, *Communicative Biocapitalism. The Voice of the Patient in Digital Health and the Health Humanities*, University of Michigan Press, 2017.

Bleakley, Alan, *Medical humanities and medical education: How the medical humanities can shape better doctors*, London and New York, Routledge, 2015.

Dean, Jodi, "Communicative Capitalism: Circulation and the Foreclosure of Politics," *Cultural Politics* 1, no. 1 2005, pp. 51-74.

Gowda, D., "Taking Time to Truly Listen to Our Patients", in Peter J. Papadakos, Stephen Bertman (Eds.), *Distracted Doctoring. Returning to Patient-Centered Care in the Digital Age*, Cham, Springer, 2017, pp. 71-86.

Jekins, Henry, Ford, Sam, Green, Joshua, *Spreadable media: Creating value and meaning in a networked culture*, New York and London, New York University Press.

Jenkins, Henry, *Textual Poachers: Television Fans and Participatory Culture*, New York, Routledge, 1992.

Lipovetsky, Gilles, *Le bonheur paradoxal* : *essai sur la société d'hyperconsommation*, Paris, Gallimard, 2016.

Lupton, Deborah, “The commodification of patient opinion: the digital patient experience economy in the age of big data”, *Sociology of health & illness*, 36(6), 2014, pp. 856-869.

Mayer, M.A., Fernández-Luque, L. and Leis, A., “Big Data for Health through Social Media”, in Shabbir Syed-Abdul, Elia Gabarron, Annie Y.S. Lau, *Participatory Health Through New Media*, Amsterdam, Academic Press – Elsevier, 2016.

[illegible] 6, https://www.propublica.org/article/stung-by-yelp-reviews-health-providers-spill-patient-secrets

Ostherr, Kirsten, “It's Time for Digital Medical Humanities”, *Field Guide: A Media* Commons Project, January 25, 2018, http://mediacommons.org/fieldguide/question/can-digital-humanities-change-way-we-study-health-and-practice-medicine-how-do-digital-re-7

Ostherr, Kirsten, *Medical visions: Producing the patient through film, television, and imaging technologies*, Oxford, Oxford University Press, 2013.

Ruckenstein, Minna, Dow Schüll, Natasha, “The datafication of health”, *Annual Review of Anthropology*, 46, 2017, pp. 261-278.

Schleifer, Ronald, Vannatta, Jerry (with Sheila Crow and a contribution by Seth Vannatta), *The chief concern of medicine: the integration of the medical humanities and narrative knowledge into medical practices*, Ann Arbor, University of Michigan Press, 2013.

Sulik, Gayle A., Eich-Krohm, Astrid, “No longer a patient: The social construction of the medical consumer”, *Patients, consumers and civil society*. *Advances in Medical Sociology*, volume 10, 2008, pp. 3-28.

Topol, Eric, *The Creative Destruction of Medicine. How the Digital Revolution Will Create Better Health Care*, New York, Basic Books, 2012.

Van Dijck, José and Poell, Thomas, “Understanding the promises and premises of online health platforms”, *Big Data & Society*, 3 (1), 2016, pp. 1-11, https://journals.sagepub.com/doi/pdf/10.1177/2053951716654173

Notes

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[1] Eric Topol, *The Creative Destruction of Medicine. How the Digital Revolution Will Create Better Health Care*, New York, Basic Books, 2012, p. VI.

[2] *Ibidem*, p. VII.

[3] Arthur André, “The Information Technology Revolution in Health Care”, in Arthur André (Editor), *Digital Medicine*, Cham, Springer, 2019, p. 3.

[4] M.A. Mayer, L. Fernández-Luque and A. Leis, “Big Data for Health through Social Media”, in Shabbir Syed-Abdul, Elia Gabarron, Annie Y.S. Lau, *Participatory Health Through New Media*, Amsterdam, Academic Press – Elsevier, 2016, p. 69.

[5] Gilles Lipovetsky, *Le bonheur paradoxal* : *essai sur la société d'hyperconsommation*, Paris, Gallimard, 2016.

[6] Arthur André, “Future Trends for Our Health-Care System”, in Arthur André (Editor), *Digital Medicine*, Cham, Springer, 2019, p. 103.

[7] José Van Dijck and Thomas Poell, “Understanding the promises and premises of online health platforms”, *Big Data & Society*, 3 (1), 2016, p. 3, https://journals.sagepub.com/doi/pdf/10.1177/2053951716654173

[8] M.A. Mayer, L. Fernández-Luque and A. Leis, *op. cit.*

[9] *Ibidem*, p. 78.

[10] Charles Ornstein, “Stung by Yelp Reviews, Health Providers Spill Patient Secrets”, *ProPublica*, May 27, 2016, https://www.propublica.org/article/stung-by-yelp-reviews-health-providers-spill-patient-secrets

[11] Minna Ruckenstein, Natasha Dow Schüll, “The datafication of health”, *Annual Review of Anthropology*, 46, 2017, pp. 261-278.

[12] Olivia Banner, *Communicative Biocapitalism. The Voice of the Patient in Digital Health and the Health Humanities*, University of Michigan Press, 2017, p. 2.

[13] Jodi Dean, “Communicative Capitalism: Circulation and the Foreclosure of Politics,” *Cultural Politics* 1, no. 1 2005, pp. 51-74.

[14] Olivia Banner, *op. cit.,* p. 49.

[15] Kirsten Ostherr, “It's Time for Digital Medical Humanities”, *Field Guide: A Media* Commons Project, January 25, 2018, http://mediacommons.org/fieldguide/question/can-digital-humanities-change-way-we-study-health-and-practice-medicine-how-do-digital-re-7

[16] https://sps.columbia.edu/academics/masters/narrative-medicine

[17] See, for instance, the opportunities of Second Life for study medicine in Kirsten Ostherr, *Medical visions: Producing the patient through film, television, and imaging technologies*, Oxford, Oxford University Press, 2013.

[18] Many times, in spite of their differences, the term is used interchangeable with other such as “health and humanities”, “biohumanities”, “humanities and medicine fields”, “humanities in healthcare”.

[19] D. Gowda, “Taking Time to Truly Listen to Our Patients”, in Peter J. Papadakos, Stephen Bertman (Eds.), *Distracted Doctoring. Returning to Patient-Centered Care in the Digital Age*, Cham, Springer, 2017, p. 80.

[20] Ronald Schleifer, Jerry Vannatta (with Sheila Crow and a contribution by Seth Vannatta), *The chief concern of medicine: the integration of the medical humanities and narrative knowledge into medical practices*, Ann Arbor, University of Michigan Press, 2013, p. 1.

[21] *Ibidem*, p. 59.

[22] Alan Bleakley, *Medical humanities and medical education: How the medical humanities can shape better doctors*, London and New York, Routledge, 2015, p. 54.

[23] *Ibidem*, p. 47.

[24] Henry Jekins, Sam Ford, Joshua Green, *Spreadable media: Creating value and meaning in a networked culture*, New York and London, New York University Press, 2013, p. 2.

[25] Henry Jenkins, *Textual Poachers: Television Fans and Participatory Culture*, New York, Routledge, 1992.

[26] Olivia Banner, *op. cit.*, p. 2.

[27] Minna Ruckenstein, Natasha Dow Schüll, art. cit., p. 267.

[28] Gayle A. Sulik, Astrid Eich-Krohm, “No longer a patient: The social construction of the medical consumer”, *Patients, consumers and civil society*. *Advances in Medical Sociology*, volume 10, 2008, p. 22.

[29] Deborah Lupton, “The commodification of patient opinion: the digital patient experience economy in the age of big data”, *Sociology of health & illness*, 36(6), 2014, pp. 856-869.

[30] Samantha A. Adams, “Sourcing the crowd for health services improvement: The reflexive patient and ‘share-your-experience’ websites”, *Social Science & Medicine*, 72(7), 2011, pp. 1069-1076.

[31] *Ibidem*, p. 1071.