



Introduction

Healthism & Self-Care: Reconfiguring Body & Life through Science & Technology

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Over the past decades technological innovations such as digital technologies, genomics, and bio-nanotechnology have been promoted as means of improving “health”, a term that was broadly defined by the World Health Organization in 1946 as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” Access to “molecules of life”, miniaturized diagnostic devices or health-related connected objects have greatly intensified and accelerated the pace of production, circulation and sharing of health data, thereby reconfiguring the traditional relationship between medicine and society.

While “biomedicalization” is often used as a term of reference to describe this social phenomenon, we choose to refer to the concept of “healthism” (“santéisme” in French) as it underscores the current development and dissemination of individual practices of biomedical techniques. People’s engagement with, or even appropriation of, new medical technologies and knowledge, both inside and outside medical institutions, have led to the opening of frontier zones of expertise and to the development of borderline practices, half-way between medicine and self-care, resulting in the multiplication of patient figures across biomedical platforms, processes and technologies. These major shifts in medical practices require a critical examination. Healthism must also be questioned if we are to gain a better view of the reconfiguration of the body and life through science and technology today.

Healthism and beyond

Robert Crawford's seminal paper in 1980 defined healthism as:

"a particular way of viewing the health problem, [that] is characteristic of the new health consciousness and movements. It can best be understood as a form of medicalization, meaning that it still retains key medical notions. Like medicine, healthism situates the problem of health and disease at the level of the *individual*'. [Crawford added that] "by elevating health to a super value, a metaphor for all that is good in life, healthism reinforces the privatization of the struggle for generalized well-being".

As a concept, healthism refers to a number of collective movements and individual practices - such as self-quantifying, on-line DNA testing or mobile health - that converge to increase the biomedicalization of everyday life. At the symbolic level, healthism is also a popular belief in a new techno-utopia, or as Lucien Sfez argued, the utopia of "Perfect Health" (Sfez, 1995). In recent years, healthism has often been likened to a new religion with jogging and diet as substitutes for prayer. As this religion of Health becomes a moral imperative today it tends to make every citizen responsible for their own health condition.

To grasp the full extent of its meaning, healthism required, in our view, closer examination. This was achieved through the international conference on Healthism and Self-care that was held on December 12-13, 2014 at the Sorbonne University in Paris. The rationale of this international conference was to bring together scholars from various disciplines (sociologists, philosophers, historians, and physicians) and to provide them with an opportunity to discuss healthism as a concept, but also to approach it as a consistent (though non-clearly demarcated) field of research, and eventually engage them in a reflection on some innovative practices and techniques that have significantly changed our relationship with healthcare. Such transformations are always difficult to circumscribe as they result from heterogeneous practices and imply the use of a wide range of techniques, including remote patient monitoring, software applications, genetic diagnostics, direct-to-consumer genetic testing, or even doping in sports. Yet the contributors to this conference have been able to successfully map all these practices and techniques while also providing original insights into healthism.

The twelve articles in this special issue, contributed by the participants of the conference, revolve around health and wellness in telemedicine, quantified-self (and doping) practices and consumer personal genomics. Mauro Turrini's article in Section 1 intends to map a brief genealogy of the concept of healthism, to shed light on the meanings currently in use, as well

as addressing the pitfalls of the issues posed by healthism. This article proceeds in two parts. First, it proposes a historical glimpse on the concept of healthism, which began as a cultural feature, or perhaps even the by-product of the well-known term “medicalization” and later gained its own autonomy. Second, it tries to explore its legacy for contemporary social sciences of medicine, by focusing on lifestyles, risk factors and the emergence of new healthy subjectivities.

Articles in Section 2 and 3 address primarily the dialectics of healthism between the clinic and the “outside”. Telemedicine, which is a remote patient monitoring practice, the quantified-self movement, as well as doping practices, are viewed as untypical ways for individuals to take ownership of medical technologies which are normally used for patient control, diagnostics and treatment. Articles in Section 4 explore the societal aspects of direct-to-consumer genetic testing, which are often seen by the medical profession and government agencies as controversial hybrid technologies involving the use of clinical genetic diagnostic tests with self-tracking devices similar to those used by self-quantifiers. Finally, Section 5 provides two different perspectives on healthism today. In his appraisal of digital health, Jacques Lucas, a French cardiologist and Vice-President of the French National Medical Board, attempts to provide a broader perspective of technomedical innovations by bridging the gap between academic disciplines. Guest researcher Federica Lucivero, for her part, provides a thorough review of *The Wellness Syndrome* (2015) by Carl Cederström and André Spicer, which was selected here for its thematic proximity with some of the major issues addressed at the conference.

Two preliminary comments are called for at this point. First, the effective or alleged protagonism of patients is worth examining as it reflects patient commitment to innovations, biomedical practices and uses of digital health devices. By addressing issues such as non-expert knowledge (Dubey), patient self-management (Maathuis & Oudshoorn), patient empowerment (Bardy), self-entrepreneurship (Ducournau), savvy consumerism (Löwy) or self re-appropriation (Memmi), the authors in this special issue acknowledge the reconfiguration of medical practices and techniques that have led patients, in recent years, to engage in new tasks and duties allowing for the protection or the optimization of their health condition or well-being. Second, the main goals of contemporary healthism may well be to question the real emancipatory value of medical innovations, but also to address the relevance of a new model of medicine rooted in the renewed principles of patient empowerment, autonomy and responsibility. In brief, the current trend toward patient autonomy and responsibility in “technomedicine” may be viewed as a way to trigger a “consumerist attitude” towards health and wellness as well as an attempt to develop the “self-care industry” and rationalize health services through the “outsourcing” of medical tasks to patients and less qualified staff.

Such reconfiguration of medical practices has major consequences for both patients and health professionals in terms of production and exchange of medical information. New informational spaces in the techno-medical ecosystem either raise new issues with regard to health and illness management or rekindle traditional debates around those issues.

The alignment of self-care with the concept of healthism is an attempt to address the effective techno-medical processes that transform health as a core value in our society. Hence, the contributors in this special issue use healthism as a critical framework that makes it possible to question the political implications of technomedical innovations at the collective and individual levels. In their articles, a patient-centric approach to medicine is used mostly to examine unprecedented ways of distributing and even producing medical knowledge. Also, this approach proves useful to better understand the social impact of new devices that are designed to self/monitor or self/control the human body (sick or healthy), prevent diseases, promote or optimize individual health.

In *Beyond traces: Towards a socio-anthropology of digital health*, Gérard Dubey focuses primarily on the ambivalent use of technological innovations that reconfigure the relationship between doctors and patients. Dubey's empirical investigation shows that both home automated healthcare systems (domohealth) and social (health) networks can either be potent agents of the de-medicalizing process implemented by the healthcare industry today, or means of "medicalizing" our "private selves" through new forms of "participatory control". What is critical, Dubey argues, is the kind of knowledge that is produced and "consumed" by patients through these connected devices. Although medical innovations in digital health may convey personal medical information, they also allow for the production of disconnected or desocialized information or, in Dubey's words, "data" and "traces", or "expert" and "common" knowledge of a disease that account for the patients' relationship to their environment and circumstances.

In *Patient empowerment: A practical approach to guide ethical decision-making in telemedicine*, Philippe Bardy aims to clarify the concept of "empowerment" and to assess its ethical implications in telemedicine today. Analysing how the patient-doctor relationship has been reconfigured through "remote home monitoring" systems, Bardy shows how patient autonomy and self-determination benefit from new medical technologies. Conversely, patient empowerment, Bardy argues, plays a fundamental role in establishing a new kind of "vital politics" based on patients' strong commitment to the healthcare process. Patient-centric health technologies are thus seen as complex emancipatory technologies, which may allow for a renegotiation of the power relationship between the various stakeholders involved in the telemedical process today.

Ivo Maathuis and Nelly Oudshoorn provide an in-depth empirical study of two telecare mobile devices designed for patients who suffer from chronic pulmonary diseases (COPD) with

a focus on patient's self-management practices. In particular, they analyse how technology assigns specific tasks and responsibilities to their users and they examine why users may accept, adjust, modify or even reject some of the "scripts" that have been designed for them. Their title, *Technologies of compliance? Telecare technologies and self-management of COPD patients*, speaks for itself. Telecare devices leave hardly any place for patients to share embodied experiences and daily routines while managing their illness. As a result, some patients end up devising their own strategies to make use of these technologies. To achieve a meaningful collaboration with health professionals, patients therefore end up challenging the rules and processes imposed by these devices which may potentially reduce them to a set of numbers.

In Section 3, contributors move away from the clinic to focus on the quantified-self movement. In *Doing things with numbers: The quantified self and the gamification of health*, Antonio Maturo examines the impact of medical data through the prism of health and fitness software applications. Designed to enhance our bodily performances, these devices are viewed as technical agents promoting and supporting new social duties and values that are not neutral. Rather, they are part and parcel of a broader socio-cultural phenomenon: "health gamification", or the "conversion" of health into quantifiable data and their subsequent rational management by individuals. Not only do these software applications act as devices of normalization, but they also become tools for "disciplinarization" or, in Maturo's terms, for "participatory surveillance": a social practice that may ultimately enable private insurance companies or even employers to exert control over people's health.

Justine Laurent's *Healthscapes of self-quantification: quantifying, knowing and improving oneself, transforming health* begins with a virtual ethnography of self-quantifiers online communities and storytelling. Focusing primarily on the centrality of knowledge in these communities, Laurent investigates practices other than "knowing" that are constitutive of self-quantifying. The realization that self-quantifiers are engaged in a number of practical "doings", often geared towards the transformation of mundane habits and change of personal lifestyles, allows Laurent to challenge the notion that self-quantification is a straightforward and problematic way of empowering patients. On the one hand, the daily measurement of variables – and the transformation of the mundane in those very variables and data – points towards a chronicization of health risks. On the other hand, the widespread use of self-quantifying practices today, which transcends the division between sick and healthy users, recasts the notion of normal health towards a constant possibility of enhancement.

Patrick Trabal's *Doping Oneself Cautiously: A Critical Approach of Healthism* closes Section 3 of this special issue with a qualitative analysis of sports doping practices among amateur athletes. Non-expert users and doctors share and co-construct knowledge on doping

practices in discussion groups on the web, leading to a sort of non-expert regulation resulting in a shared "sense of measure" which is subsequently adopted by amateur athletes. This, in turn, leads to a move away from traditional doctor-patient relationships and to the rise of an alternative "counter-knowledge" produced by non-experts. Trabal assesses these outcomes against his own critical view on healthism combining Foucault's concept of "biopolitics" with a phenomenological approach inspired by John Dewey.

Articles in Section 4 attempt to review the concept of healthism against the analysis of contested areas located between medicine and non-medicine.

The historian of medicine Ilana Löwy warns us about the so-called novelty of "patient empowerment". In *From savvy consumers to informed risk managers: Shifting images of medical self-care*, Löwy compares two types of cutting-edge medical interventions, namely laparotomy and genetic data processing, which became popular in the United States in the late 19th century and the early 21st century, respectively. As Löwy reminds us, many women would die after a laparotomy, which was a cutting-edge surgical operation actively sought after by patients in the late 19th century. Likewise, few specific mutations of BRCA1 (the gene associated with the increase of breast and ovarian cancer) have been actively supported by Jewish communities, despite their ethnic/racial connotation (BRCA1 is very frequent among the ashkenazi population). "Pro-active users of health information and interventions are not an invention of the internet era", writes Löwy, dating back this phenomenon to the turn of the 20th century, when the uptake of technological innovations by patients and users (not only physicians) was already a common practice.

In *Au delà du santéisme, la génomique en version "do-it-yourself"*, Pascal Ducournau proposes to go beyond the limits of traditional healthism by analysing an emerging generation of medical devices: direct-to-consumer genetic tests (DTC GT). According to Ducournau's thorough and qualitative analysis of users' motivations, practices and findings, people want these tests to track information about the predisposition to the most common causes of death, or the presence of some hereditary mutations. The possibility to convert our physical condition into a set of data that are measurable, quantifiable, and mobile allows for the concrete realization of the notion of "health capital" (*capital santé*, in French). The personalization of health and wellness as well as the democratization of the entrepreneurial spirit that supports it, Ducournau argues, are indeed new models threatening to supplant Public health service for the benefit of a more personalized, but also less equalitarian and possibly less efficient model of medicine.

Mauro Turrini's *Practicing the biomedicine to come: Direct-to-consumer genetic testing, healthism and beyond* aims to show the virtues as well as the limits of healthism and focuses on other aspects of DTC GT, often neglected, namely leisure and sociability. The responses to

consumer personal genomics usually alternate between an acceptance of DTC GT as effective tools for patient empowerment and a deprecation of DTC GT as consumerist applications for biomedical research. Interestingly, DTC GT users end up assigning great importance to the recreative and social practices that are underpinned by genomic data. If healthism is relevant in describing the many changes entailed by new genomic technologies, it fails to address the different values attached to the production, interpretation and sharing of medical information, and it does not do justice to the new forms of bio-sociality related to the connectivity and the operability of information enabled by the Internet and ITs.

In *Autobiologies: Making sense of engagements with healthcare technologies*, Anna Harris, Susan Kelly and Sally Wyatt provide valuable insights into non-medical forms of patient engagement with healthcare technologies. "Autobiology", a blend of "autobiography" and "biology", is coined to characterize "the study of and the story about one's organism", and refers to a minor genre of medical storytelling which differs from illness narratives, in that it tells the encounter with one's biology, as it is reconfigured by new technologies. While acknowledging the importance of "old technologies" such as home pregnancy tests, the authors focus primarily on the new opportunities provided by mobile communication technologies allowing for the telling of stories by "non-celebrities", who spontaneously try to make sense and share the processes of self-making inherent to the use of new technologies. Pursuing Turrini's effort to apply the concept of bio-sociability, Harris, Kelly and Wyatt propose the concept of "autobiology" as an alternative means of keeping together the creative, playful as well as the economic dimensions of a new form of patient engagement with medical technologies.

Dominique Memmi concludes Section 4 by reviewing the original tenet of "anatomy as destiny" in traditional healthism, which was introduced by Kenneth Irving Zola in its seminal article on healthism (Zola, 1977). In *Denying human biology as destiny*, Memmi unfolds the historical process that has prevailed over the last fifty years, which she calls "the physical re-appropriation of the self". Drawing on Norbet Elias' works on self-control and shame, Memmi describes new stances towards birth and death which are strategies designed to take control of one's individual body. Such strategies rose from the spontaneous and popular conflicts revolving around Nature, the State and, ultimately, Society which emerged in the 1960s. Such historical transformation triggered a radical change in life management as a whole leading to sanctioning any unmediated control over the human body while shaping a new paradigm for biopolitics. This, in turn, reflected the decline in State control and the increasing centrality of individual subjects and body, which led Foucault's disciples to refocus their attention to "life itself" and "bare life".

Overall, the essays in this special issue present different perspectives on practices and techniques that appear to assign a new role to the patient within the framework of a new

relationship with illness, health, and wellness. One of the main difficulties for researchers, however, was to delineate the contours of the medical areas under scrutiny. Indeed, telecare technologies, self-care, quantified self practices or direct-to-consumer genetic tests tend to converge today, thus blurring the lines between prevention and treatment, but also between preservation, monitoring and enhancement for health and/or wellness purposes. The papers in this special issue aim to bridge the gap between clinical procedures, clinical genetic tests and consumerist devices such as DTC GT, which lie at the intersection of health issues and body practices (Memmi), health and leisure (Maturo, Turrini), data and narratives (Harris, Kelly and Wyatt, Laurent), etc. Patient-centric care turns out to bring medical values and practices into society in a very pervasive way while getting people to actively engage themselves in the care process.

By providing a useful framework for bringing together clinical, epistemological and political perspectives on patient care, healthism is still a valuable concept that can be used, articulated, updated and applied to new technologies that assign tasks and duties to patients. As many studies suggest, healthism may provide a useful critical background to question new buzzwords such as "patient empowerment" (Löwy, Bardy) or "self—management" (Maathuis and Oudshoorn) and address the theory of knowledge that is implicit in them (Laurent). These studies also signal another key benefit of healthism, as a critical tool: to allow for the assessment of political implications resulting from human body quantification (Ducournau). In most papers, the critique of the production, management, circulation of, and fascination for, bio-data highlights the importance of big data analysis, healthcare practices and techniques (Dubey). The multi-layered exploration of healthism – the gaze on body and life, the new morality based on the individual hyper-empowerment, the injunction to remain (or become even more) healthy (that applies to healthy people too) or the elaboration of new forms of health-based disciplinary control – are but a few examples of how accurate the concept of healthism still is today. At the same time, it is also crucial to acknowledge the critical limits of healthism, especially when it is applied to practices related to the production, interpretation and circulation of bio-data and to the issue of sociability. It is equally important to remember that big data practices lie at the core of the well-being and healthcare sectors today. It is therefore hoped that the papers presented in this special issue will contribute to flesh out the perspectives of healthism and make sense of the evolution of patient-centric healthcare (and self-care) today.

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