
Digital FairGround: Explorations of the Patient Experience between Social Justice and the Virtualization of Health and Illness.

I. Introduction: Defining the Patient Experience.

Ephemeral, vague and epistemically deficient as the constitutive or core criteria of our contemporary democratic societies – identity, social justice, and equality – may already be, they have been subject to even further re-qualification in two respects: They have become *digitalized* and they have become *biologicalized*. Tentatively, it could be argued that the first of these two qualifications has to do with information *proper*, whereas the second touches largely upon somatic norms. The Sociological Imagination, on the other hand, in following contemporary systems and complexity theory¹, would argue that biological issues of the somatic kind are, too (or are at least translatable into) information; however, a very specific kind of information. The most salient concept of information became defined by Claude Shannon and Warren Weaver in the 1940s², absorbed by the cybernetics movement in the Macy conferences, and transfused into sociological theory from Talcott Parsons to Niklas Luhmann. The story of biology, cybernetics and information theory has been told from various angles, including the two most impressive accounts by Lily Kay and N.Kathryn Hayles³. In light of Hayles account, we begin to understand that, indeed, the concept of information – as outlined by Shannon/Weaver – that we have taken for granted in the social (and most other) sciences for the past few decades, is a limited one to begin with; moreover, in its inception, it was neither without alternative⁴ nor designed by its “creators” to become this encompassing and comprehensive in satisfying a highly subjective human need for simplifications and universalization. However, it goes without saying that medical knowledge is constituted as information, whether it is obtained and applied by health care practitioners (such as doctors or nurses), health care administrators/legislators, or the lay-people who are care recipients and

¹Sylvia Walby “Complexity theory, systems theory and multiple intersecting social inequalities“, *Philosophy of the Social Sciences*, 37 (4/2007): 449-470

²Warren Weaver, Claude Elwood Shannon. *The Mathematical Theory of Communication*. (Chicago: University of Illinois Press, 1963)

³N. Katherine Hayles, *How we became Posthuman*. (Chicago: Chicago UP, 1999); Lily Kay, *Who wrote the book of life?* (Cambridge, MA: Harvard UP, 2000)

⁴Where Shannon/Weaver define, in my overly simplified description, information as the existence of a signal that stands out from noise but is not reviewed for content or meaning, Donald McKay suggested a concept of information that could account for meaning, and which social theorists have left largely unexplored.

patients. If we take this into account along with three developments in the history, philosophy, and sociology of biomedical science lead to a different conceptualization of the relationship between society, digitality and biology based on a more complex concept of information which deviates from the Shannon/Weaver definition, precisely in leaving information slightly vague and intentionally underdefined⁵; and accounts for the results presented in recent literature on the intersection between health care, medicine, and citizenship (aka the demarcation of the boundary between collective and individual identity in contemporary democratic societies), an interrelationship that is largely known under the heading *biopolitics*.

Without having the room here to go into a saturating discussion of all the details in this little essay which already has to satisfy too many intentions as it falls somewhere between critical review, exploratory essay, and “writerly” text⁶, I will only name not explicate that these “three developments” are:

- a. Actor-Network Theory (ANT) and its relation to semiotics, as outlined by Bruno Latour and John Law⁷
- b. The continuation of Michel Foucault's seminal interventions by Paul Rabinow, Susan Pickard and Nikolas Rose on biopower and its politics⁸
- c. And a notion introduced by Christopher Bayly, which is now widely, while still largely implicitly, accepted by leading science historians such as for example Simon Schaffer (2008): that the constitution of knowledge from information is dependent on

⁵ When it reaches the conceptual level, this problem has become understood as the *epistemic deficiency* of concepts: Paul Boghossian “Analyticity Reconsidered”. *Nous*, (1996); 30, 360 – 391; Paul Boghossian “Epistemic Analyticity: A Defense.” *Grazer Philosophische Studien*, 66 (2003): 15 – 35; Ross, Sherry Tuttle “Understanding Propaganda The Epistemic Merit Model and Its Application to Art.” *Journal of Aesthetic Education*; 36 (2002): 16 – 20

⁶By which I refer, of course, to Roland Barthes's distinction between *readerly* and *writerly* texts. The prior being closed and predeterminative, whereas the latter is an effort to engage the reader to pick up where the writer has left off and continue to go through the door the writer has opened. The writerly text is, in my view, largely neglected today while I consider it to be the natural genre for critical theorists. Employing the technical vocabulary that I have recently become immersed in, it could be said that *readerly* texts serve as *constraints*, whereas *writerly* text are meant to *enable* readers.

⁷Referring not to semiotics in general, but the semiotics of A.J. Greimas:

Bruno Latour “How to talk about the body” .*Body&Society*, Vol.10 (2/3, 2004): 205 – 229; Bruno Latour *Reassembling the social*, (Oxford: Oxford UP, 2006); Law, John “Actor Network Theory and Material Semiotics” version of 25th April 2007, available at <http://www.heterogeneities.net/publications/Law2007ANT-andMaterialSemiotics.pdf>, (last accessed on 18th Feb. 2009); Algirdas Julien Greimas *The Social Sciences. A Semiotic View*. trans. Frank Collins and Paul Perron. (Minneapolis: University of Minnesota Press, 1989)

⁸ Michel Foucault. *Naissance de la Clinique* (Paris: Presses Universitaires de France. 1963); Susan Pickard “The role of governmentality in the establishment, maintenance and demise of professional jurisdictions: the case of geriatric medicine” *Sociology of Health and Illness* (2010); online first; Pickard Susan “Governing old age: the ‘case managed’ older person” *Sociology*; 43 (1/2009): 67 -84; Susan Pickard “Citizenship and consumerism in health care: a critique of citizens' juries” *Soc Policy Adm* ; 32 (3/1998): 226 -244; Nikolas Rose *The Politics of Life Itself*. (Princeton: Princeton UP, 2006); Nikolas Rose “Molecular Biopolitics, Somatic Ethics and the Spirit of Biocapital” *Sociology of Health and Illness* Vol. 5 (2007): 3 – 29; Paul Rabinow *French Modern: Norms and Forms of the Social Environment*. (Chicago: University of Chicago Press, 1995); Paul Rabinow *Anthropos Today: Reflections on Modern Equipment*. (Princeton: Princeton University Press, 2003)

the gap between information and information order; respectively, knowledge is actually not produced from information but from ordered information⁹.

The sum of these cues is that, in actual practice, information cannot merely be defined to mean “the difference of signal from noise”. Instead, information, to be practical, may well be embedded in or analogous to meaning¹⁰; most importantly, though, information exists only in relation to practices (which indicates, in my view, that we need a change in our understanding of agency and of semantics with relation to practices as a form of semantic agency).

In the past few years and with some very *practical* consequences, contemporary biomedical knowledge, the current plethora of definitions of health and illness, and the channels of access to both public health information and adequate care (which is a key issue in the discourse of social justice and equality), have been reconstituted interdependently under the conditions of *digitalization* and *biopolitics*. On the biopolitical level of epistemology, these consequences have been accounted for Nicholas Rose, in the analytical differentiation of the *molar gaze* from the *molecular gaze* and the emergence of the notion of *our neuro-chemical selves*. On the empirical level, in the sociology and anthropology of medicine, the most crucial question, that we are presently just in the beginning of asking, is: “What does this reconstitution mean for the patient and the patient experience?”

Traditionally, medical sociology used the role-concept for a good part of the 20th century to help us understand the patient-experience; with a change of the prerequisites both patient experience and social scientific concepts have changed. As the basic category in the concept of the sick-role, as defined by Talcott Parsons¹¹, had structured how social science viewed the patient, the medical profession and doctor-patient interaction from the 1950s into the 1980s. In turn, this kind of sociological imagination, including the time-lag that always exists between science on the one hands and, on the other, its publics and policy-making, has also shaped health-care and medical practice¹²: To sum up, Parsons's notion of the sick role was

⁹This is, by the way, not exactly the same as bald (social) constructivism, in so far as in constructivism, information that qualifies as “real” is never *actually real*, whereas in this “info-order” perspective, information orders are “real” and information is *actual*. I must emphasize that this analytical point, which we have no space to explicate further, is not merely pertaining to any kind of jargon nor splitting of hairs. The information order problem circumscribes on a very practical level the issue that the philosophical problem of *epiemic deficiency*.

Simone Schaffer, “Newton On the Beach: The information order of the Principia Mathematica. SHC Lecture”. (San Francisco, CA: Stanford Humanities Centre, 2008); Christopher Bayly, *Empire and Information*. (Cambridge, UK: Cambridge UP. 1996)

¹⁰ Donald M. McKay *Information, Mechanism, and Meaning*. (Cambridge, MA: MIT Press, 1969)

¹¹ Talcott Parsons *The Social System*. (Glencoe, Ill.: Free Press. 1951)

¹²Keith Wailoo “Sovereignty and Science: Revisiting the Role of Science in the Construction and Erosion of Medical Dominance” *Journal of Health Politics, Policy and Law* 29(4-5/2004): 643-660

the result of his early-life interest in the medical profession in the 1920s and 30s, a career that he had begun preparing for, in the footsteps of his brother, before eventually hitting the career-path of social theorist. Not to let his intimate knowledge and retained interest go to waste, he designed a study of the medical profession around 1932/3, which he eventually received funding for and lectured on, but which he never published. Its conceptually most salient statements, however, including the definition of the sick-role, saw the light – outside of a classroom – in his seminal *The Social System in 1951*: According to him, *being sick* is analogous to a form of 'sanctioned deviance'. This social functionalist view of sickness states, thus, that a sick individual cannot be expected to participate in the production of society in the usual way and has thus be considered exempt. In the same way that deviance needs to be addressed by police, this role concerning the sick falls to the medical profession (which was, in some regard, also the historic function of the *Polizey*, with regard to disease prevention through hygiene). To have fallen ill means that one is not merely physically sick, one falls into a specifically patterned social role of *being sick*. Once that role is attained by an individual, it is not just a mere statement of fact or a condition, it with its come social habits and rights as well as obligations deriving from numerous social norms that surround it: i.) The sick person is not responsible for their condition and ii.) the sick person is considered exempt from normal social roles, such as labor, but this also necessitates that s/he is looked after iii.) a sick person is expected to do what is in his/her power to try to get well, and iv.) to seek technically competent help and cooperate with the medical professional. The legitimation of the person occupying the sick-role follows from the authority of the medical practitioner. Respectively, the pertaining norms are constructed to promote compliance with the medical regime to facilitate restoration of health and, subsequently, re-assumption of the “normal” roles the persons is expected to occupy. Since Parsons in the 1940s and 50s had begun analyzing such processes additionally from the point of view of behavior, he was looking into the *motivations* of those occupying a role and linking them to questions of social expectations and double contingency, group formation and integration, solidarity, and the question of authority and legitimacy. In the late 1970s and early 1980s, Paul Starr¹³ and a number of the new generation of sociologist had begun to re-assess the situation, because Parsonian theory in general had gone out of fashion, and discussion of health care reform necessitated new ways of thinking¹⁴. In particular, a range of scholars picked up the critical idea of the *medicalization of society*, a term that was

¹³Paul Starr *The Social Transformation of American Medicine*. (Basic Books, 1982)

Paul Starr “American Medicine's Transformation (or not?) - A Quarter Century's Perspective“. (Policy History Conference, May 31, 2008)

¹⁴Although serious reform efforts in the health care sector in the U.S. have been effectively stalled since and remained so until legislation by the Obama administration; although the actual fate of this reform will probably not be decided for another decade of court-proceedings and elections.

made famous by Michel Foucault but disseminated in the U.S. largely due to the works of Peter Conrad¹⁵ and Ivan Illich¹⁶.

In the past fifteen years, the still somewhat vague concept of the patient as a “managed case” has supposedly(!) emerged from within the discourse of go(u)vernmentality-theory of Michel Foucault, substituting the prerequisites contained in the sick-role with “more modern” conceptualizations of normalization of management practices in patient governance, which the relevant authors – such as, Susan Pickard, or Carl May – consider key to grappling with the construction of *subjectivities*. However, I consider the notion of *subjectivities* to be tied much closer to the idea of the *actually lived patient experience* (instead of over-emphasizing either the sick-role or “managed case”-role) and I think that this notion is emerging implicitly in writers such as Nikolas Rose or Anne-Marie Mol¹⁷ – both of which drawing heavily on their empirical experiences in conducting research¹⁸. For a variety of reasons, I feel that we need to

¹⁵Peter Conrad. *Identifying Hyperactive Children: The Medicalization of Deviant Behavior* (expanded edition, forthcoming from Ashgate Publishers, 2006. originally: Lexington: D.C. Heath, 1976); Peter Conrad, *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*. (Baltimore: Johns Hopkins University Press, 2007.

¹⁶Ivan Illich *Medical Nemesis*. (London: Calder&Boyers 1974)

Perhaps, Thomas Szasz should also be mentioned, because he was certainly an influential voice. However, despite his admirable intentions and impressive intellect, Szasz's notoriously ideologic and dogmatic stance on the one hand, and, on the other, his partnership with the cult organization known as Scientology, have largely undermined his credibility and legitimacy.

¹⁷Carl May „The Clinical Encounter and the Problem of Context“ *Sociology* 41 (2007): 29 – 45

Carl May, T. Finch „Implementation, embedding, and integration: an outline of Normalization Process Theory“, *Sociology* 43 (3/2009): 535-554; Susan Pickard „The role of governmentality in the establishment, maintenance and demise of professional jurisdictions: the case of geriatric medicine“ *Sociology of Health and Illness* (2010); online first; Susan Pickard „Governing old age: the 'case managed' older person“ *Sociology* 43 (1/2009): 67 -84; Susan Pickard “Citizenship and consumerism in health care: a critique of citizens' juries” *Soc Policy Adm* 32 (3/1998): 226 -244; Jonathan Matusitz, Gerald-Mark Breen „E-Health: A New Kind of Telemedicine” in: *Social Work in Public Health*, Vol. 23 (1/2007): 95-113; Annemarie Mol *The body multiple*. (Chapel Hill, NC: Duke UP, 2002) Nikolas Rose “Molecular Biopolitics, Somatic Ethics and the Spirit of Biocapital” *Sociology of Health and Illness* Vol. 5 (2007): 3 – 29 ; Stephen A. Rains “Health at High Speed: Broadband Internet Access, Health Communication, and the Digital Divide.” *Communication Research*, Vol. 35 (3/Jun/2008): 283-297; Paul Starr “Professionalization and Public Health.” *J Public Health Management Practice* Suppl. (Nov. /2009): 26 – 30

¹⁸I also would very much like to stress two points:

First, I do not mean to say that Pickard or May do not engage in “empirical research”, quite on the contrary, they are both fine researchers whose contributions to the contemporary discourse I value very highly. I only mean to say that I suggest a shift of focus towards an even more patient-centered research.

Secondly, I wish to counter the “Parsons-bashing” that has become a bit of a habit of many professional sociologists. Parsons, which a really close look at his published works – and moreover, his unpublished works – reveals, was not just acutely aware of the historical prerequisites of the social history of medical science, he was, above all, also conducting empirical research, focusing on both patient experience and practitioner experience. Many of his statements were made to diagnose the normative elements of social actions and processes in his time and place, and he, more than many others, was seriously aware of the limitations that a situational diagnosis brings with it. His description of *existing* normative elements in medical practice and how they *are* working, did not mean that he was to say that this is how they *should* be working at any time or in any place. He was a strict Simmelian or Weberian in that regard. Just like the work of Foucault, his came with a clear understanding of the ephemeral nature of practical scholarship, and, respectively,(without any denigration or pejoration) he repeatedly expressed, for him like for Kant or Jaspers, that neither his interest nor his job was it to produce works of contemplative/fictional philosophy that he thought was the interest of men like Hegel, Heidegger, or Schuetz.

re-assess the theoretical situation of research with regard to the empirical aspect, the experiences of patients (and practitioners)¹⁹ and what makes them possible:

First, the “managed case” implies the existence of predetermined patient careers and trajectories, which in actuality individual patients may not always cohere to (either objectively or subjectively); since subjective experiences play a role in the healing or care process (keyword: “psychosomatic medicine”), the gap between the care/healing pathway (or therapy regimen) and the *actual* individual care/healing development may turn out to be fairly wide. This re-emphasizes that, while it is nearly impossible to find a coherent definition for concepts of *health*, *illness*, and *good life* (indeed, this particular discussion is still raging through many academic journals), we can at least elucidate the process, how people adopt or create these concepts for themselves and their individual lives and medical practice. The first step, in my point of view, is to accept that all concepts used in medical practice (such as *health* or *illness*) are largely epistemically deficient and that we have a long road ahead of us in getting a handle on what I have called the *information order problem*.

Secondly, the “managed case” paradigm is actually not a new concept or practice, in so far as we associate it with the latter 20th century. It is an older concept; when and how it was initially created is something we have not yet been able to account for properly; however, it became institutionalized as a technical conceptualization as early as 1857 with the publication of Thomas Laycock's *Lectures on the Principles and Methods of Medical Observation and Research*. If we are to understand where many contemporary practices and concepts come from, how and why they both *enable* and *constrain* us, we stand a better chance at correcting mistakes – this same notion was, in fact, the theory-political task of the Kantian idea of *Aufklärung* (Enlightenment: *Sapere Aude!*) and of Foucault's *genealogy* as forms of *critique*.

Finally, the more profound and continuously present concepts in Foucault's writings on medicine are not *go(u)vernmentality* and *subjectivity* but: *experience*, *positivities*, and *practices*. Therefore, as *critical theorists* and in future research, we should try to illustrate in what ways the conceptualizations of Nicholas Rose, Susan Pickard, and Carl May – in short: biopolitics&molecular gaze, governmentality&case-management, and normalization processes – reshape the epistemic setting of the patient experience, the positivities, and the practices in

¹⁹I will not delve into the vast literature of narrative and patient-centered medicine, which would certainly be called for, in order to describe the concept of “patient experience” in a comprehensive fashion. For the constraints of space and topic, the focus of the conflation of *digitalization* and *biologicalization*, I will only draw up a few discontents I have with the current use of the “management” metaphor, to show why we need to redraw it for future research and practice.

light of the constitutive criteria of democratic society – justice, equality, and identity – along the two axes of *digitality* and *biologicality* towards the emergence of a novel form of patient experience: the *virtual patient*.

II. *Virtualizing the patient.*

In academic circles it has now long been widely accepted that the modern concept of citizenship has become re-defined as *biological*, that as people we are both subject to and participative in *biomedical citizenship*²⁰. The mutually interdependent effects of yet another socio-cultural re-transformation in both civil society and biomedical practice has, at the same time, been largely either obscured or has been unduly welcomed in current research literature, governance and journalism on the practice of health care. Research in *digitalization* or, in other words, *virtualization* in health care and biomedical practice generally seems to underestimate the effects of two mutually reinforcing processes, *hyperspecialization* and *universalization*, which, in my opinion, largely constitute and account for what is meant by *virtualization*. Donald Levine²¹ has argued that the effects of *hyperspecialization* – the overincrease, prevalence, and over-acceleration of the process differentiation and specialization – are not entirely positive and he has, thus, suggested a guideline for revisions in the Liberal Arts curriculum as a means of countering the negative effects of this process. Thereby, Levine is perhaps the first but certainly the most eminent to make hyperspecialization both a *fait sociale* and a primary concern of humanities and liberal arts academe²². His diagnosis of the negative effects of the hypostasizing tendencies of the process of social differentiation is, in my view, not merely applicable to the system of health care and biomedicine, it should also be combined very effectively with ideas and criticisms by Paul Starr. Starr²³ warns of the effects of simplifying political categories and ontologizing (or reifying) these into policies and administrative path-

²⁰Adriana Petryna *Life Exposed: Biological Citizens after Chernobyl*. (Princeton, NJ: Princeton University Press, 2002); Aihwa Ong „Mutations in Citizenship“ *Culture, Theory&Society* 23 (2006): 499 – 505; Nikolas Rose *The Politics of Life Itself*. (Princeton: Princeton UP, 2006)

²¹Donald Levine *The Powers of the Mind*. (Chicago: Chicago UP, 2006)

²²This is part of the reason why I argue that future higher educational and research programs, that try and educate specialists from within the field of medical practice (such as for example nurses, who are an engine of progress towards better health and better care, see the 2010 report on *The Future of Nursing: Leading Change, Advancing Health* by the Robert Wood Johnson Foundation) and which we can summarily call *medicine studies* for our tentative business here, must come not from within biomedical or (business)-administrative science (as e.g. Public Health), but it must, instead, equip practitioners with soft skills that are usually found in the humanities and social sciences. This is not to mean that there aren't some very promising efforts underway, for example the medical humanities initiatives by ISO-CYTE - Research Center on Health, Society, Science and Technology in Buenos Aires, journals such as *EÁ* or *Philosophy, Ethics, Humanities in Medicine*, or the degree program in health communication at Boston's Emerson College. But there is still a lot of work to be done, specifically in the development areas of curriculum and research direction&coordination. Germany, for example is currently in the process of curbing any development in such directions, with public media engaging in hate campaigns against complementary medicine or state universities, such as the Goethe University Frankfurt am Main (once the home of Critical Theory with Habermas, Horkheimer, and Adorno) closing down its medical sociology department.

²³Paul Starr “Social Categories and Claims in the Liberal State“. In: *Social Research* Vol.59, 1992: 263 – 295

ways²⁴. The failings of recent health care reforms and the discontents of biomedical progress are just a more concretized²⁵ occurrence of this phenomenon.

Moreover, I argue that we can identify and define a social and epistemological process of transformation in the production of (practical) medical and health care knowledge, which is the result of the combination of the two processes that Levine and Starr describe: *Virtualization*. I consider this concept to describe the continuous, transformatory process of *virtualizing* biomedical practice and research towards the production of practitioners, patients, and medical concepts of normalcy and pathology that fit in with the demands of a particular in-

²⁴After a fashion, he reiterates Whitehead's notion of the fallacy of misplaced concreteness in political sociology.

²⁵Paul Starr "American Medicine's Transformation (or not?) - A Quarter Century's Perspective". Policy History Conference, May 31, 2008

Paul Starr "Professionalization and Public Health." *J Public Health Management Practice* Suppl. (Nov. /2009): 26 – 30

formation- and knowledge-based economic regime²⁶. This process has led to the emergence of the ideal-type of the *virtual patient*.

The following account suggests itself as a corollary found in the investigation of the existing literature: As a *virtual patient*, a suffering individual is reduced to a bureaucratically manageable case-file. Patients, under a dogma of self-care²⁷, are left to their own devices to navigate between the life-words that they actually occupy on the one hand, embodied in their unique

²⁶ Nadia Rubaii-Barrett, Wise, Lois Recascino. "Disability Access and E-Government: An Empirical Analysis of State Practice" *Journal of Disability Policy Studies* Vol. 19 (1/Summer/2008): 52-64; Izet Masic, Emina Suljevic, "An Overview of E-Health Implementation in Countries, Members of the European Union." In: *Acta Informatica Medica*, Vol. 15 (4/2007): 242-245

Jonathan Matusitz, Gerald-Mark Breen „E-Health: A New Kind of Telemedicine” in: *Social Work in Public Health*, Vol. 23 (1/2007): 95-113; Grenville Hadley, M.Mars, "Postgraduate Medical Education in Paediatric Surgery: Videoconferencing — A Possible Solution for Africa?" in: *Pediatric Surgery International*, Vol. 24 (Feb/2008): 223-226.

The *Virtual* delimits a selection of participants, which already exists in the labor markets. The ability to navigate the labor marker, that means to have access to jobs, depends increasingly on accepting both *specialization* and *universalization*: One must have a particular skill set that fits precisely into a certain, narrowly defined job-niche, while being able to present those skills in a universally acceptable form (often using a "digital rationale"), which demonstrates that the job-seeker can inter-connect *universally*.; see, with special reference to exclusion/inclusion and equality:

Jan A. G. M. Van Dijk, *The Deepening Divide: Inequality in the Information Society*. (Thousand Oaks, CA: Sage. 2005); Mark Warschauer. *Technology and Social Inclusion: Rethinking the Digital Divide*. (Cambridge, MA: MIT Press. 2003); Joo-Young, Jung Jack Linchuan Qiu, Yong-Chan Kim "Internet Connectedness and Inequality" in: *Communication Research* 28:507–35; Cushla Kapitzke "Information Technology as Cultural Capital: Shifting the Boundaries of Power." *Education and Information Technologies* 5 (2000):49–62;

Eszter Hargittai, K.Dobransky „The Disability Divide in Internet Access and Use.“ *Information, Communication and Society*. 9 (3/2006): 313-334; Eszter Hargittai. (2008). [The Role of Expertise in Navigating Links of Influence](#). In *The Hyperlinked Society*. Edited by Joseph Turow and Lokman Tsui. Ann Arbor, MI: The University of Michigan Press. 85-103; Eszter Hargittai, A. Hinnant (2008). „Digital Inequality: Differences in Young Adults' Use of the Internet.“ *Communication Research*. 35 (5/2008):602-621; Eszter Hargittai, G. Walejko. „The Participation Divide: Content Creation and Sharing in the Digital Age.“ *Information, Communication and Society*.11(2/2008): 239-256; Eszter Hargittai „[The Digital Reproduction of Inequality](#).“ In: *Social Stratification*. (Edited by David Grusky. Boulder, CO: Westview Press. 2008: 936-944.); Eszter Hargittai, . „[Cognitive Ability and Internet Use Among Older Adults](#).“ *Poetics*. (Journal of Empirical Research on Culture, the Media and the Arts) 34 (4/2006): 236-249; Donna L. Hoffman, Thomas P. Novak "Bridging the Digital Divide: The Impact of Race on Computer Access and Internet Use." in: *Science* 280 (1998):390–91; Robert W. Fairlie "Race and the Digital Divide". *Contributions to Economic Analysis & Policy* 3, (2004): Article 15 Retrieved May 4th, 2008 at: <http://www.bepress.com/bejeap/contributions/vol3/iss1/art15>; Andy Dickerson, Francis Green. "The Growth and Valuation of Computing and Other Generic Skills.in: *Oxford Economic Papers* 56 (2004):371–406; Paul DiMaggio and Joseph Cohen "Information Inequality and Network Externalities: A Comparative Study of the Diffusion of Television and the Internet" Working Paper #31, (Fall 2003) retrieved March 15th 2011 at: <http://www.princeton.edu/~artspol/workpap.html>; Paul DiMaggio and Eszter Hargittai "From the 'Digital Divide' to 'Digital Inequality': Studying Internet Use As Penetration Increases". Working Paper #15, (Summer 2001) retrieved March 15th 2011 at: <http://www.princeton.edu/~artspol/workpap.html>; Paul DiMaggio, et al. . [Digital Inequality: From Unequal Access to Differentiated Use](#). In *Social Inequality*. (Edited by Kathryn Neckerman. New York: Russell Sage Foundation.2004: 355-400.) ; David H. Autor "Wiring the Labor Market." *Journal of Economic Perspectives* 15, (2001):25–40; David H.Autor, Lawrence F. Katz, and Alan B. Krueger. "Computing Inequality: Have Computers Changed the Labor Market?" *Quarterly Journal of Economics* 113, (1998):1169–83; Daron Acemoglu "Technical Change, Inequality, and the Labor Market." *Journal of Economic Literature* 40, (2002):7–72;

Philippe Aghion, Peter Howitt. "Wage Inequality and the New Economy." *Oxford Review of Economic Policy* 18, (2002):306–23.

organism that is embedded in a individual nexus of natural, social, and cultural environments²⁸; and, on the other hand, the *virtual* health-care regimes that rely on information-processing procedures, bureaucracies, and to navigate the predetermined patient-career trajectories. *Self-care* is encouraged, however, in the increasingly *digitalized environment*, its exercise is possible only for those who can successfully bridge the digital divide.

Therefore, we can draw the following two conclusions:

1. Those who live on the wrong side of the digital divide are left behind (both economically in access to information in and about labor-markets and in regard to access to health care. These two dimensions have shared, mutual effects, with health and health information about a job-seeker as prerequisites to labor-market access, whereas only “proper” employment leads to “proper” health care access).

2. True *care for the self* is not enabled.

I suggest that, in order to create both a just and cost-effective health care system, we need to provide both a better conceptual framework and a better institutional framework²⁹. Such a conceptual framework would have to be constructed with the contingency to account for the developments in biomedical and mental health research in a way that *enables* patients, doctors, and caregivers to cooperate in favor of the individual patient’s health, the *enablement* of the autonomy of the individual patient's health and care decisions, and his/her positive development of *life-course* – with *life-course* understood to be the modern meaning of: life, liberty and pursuit of happiness in matters of health-care (this demand, which is based on a Kantian and a Durkheimian perspective and most forcefully argued for in the voice of Onora O’Neill³⁰).

²⁷Stewart J.Murray „Care and the self.“ *Philosophy, Ethics, and Humanities in Medicine* Vol.2, (6/2007)

²⁸Stingl, Alexander I. “ADHD in a Science studies Perspective”, *Health and Environment*, edited by Helen Kopnina, Hans Keune (New York: Nova Science Pub., 2010: 157 – 186)

²⁹With regard to practitioners or intermediaries who execute and continually improve these frame-works, finding practical solutions through research and preparing practitioners and intermediaries in their implementation is a novel task, because it requires embedding health solutions in the actual life-worlds of care-recipients. With the population growing ever older and the rise of chronic disorders (or at least, the increase in permanent treatment options), as well as the need for transcultural interpretation of an increase in multi-/intercultural patient populations (all soft skills taught in the humanities&liberal arts) , this sends us back to the drawing board to create adequate education and research programs. Respectively, the demand I make for new and better programs in *medicine studies*, the way we have (and still need more of) in STS and science studies, is well justified.

³⁰ See the excellent summary of O’Neill’s relevant ideas in: Richard E. Ashcroft, „Kant, Mill, Durkheim? Trust and Autonomy in Bioethics and Politics“ in: *Studies in the History and Philosophy of Biological and Biomedical Sciences* Vol. 34, (2003):. 359 – 366

III. The emergence of the virtual patient

While I do not mean to say that they are in any way trivial or superficial, contemporary academic debates on *biopsychosociality*³¹, public health, and patient autonomy are often lacking a satisfying account of the underlying mechanism that guides the formation of concepts in biomedical science, the transformation of the doctor-patient relation, and biomedical ethics. This mechanism is very adequately described in conceptualizing the ongoing process of *virtualization*. Carl May's³² work on normalization theory helps us understand, if not the emergence of such mechanisms, at least their implementation: *Normalization* refers to the embedding of routines and practices in everyday life through interaction chains. This process is very different for the variety of actors involved in the patient experience. For each patient, a first and crucial factor is whether the patient experience itself is merely a transitory one, more or less enduring, or even permanent. Although the ongoing “medicalization of society” must be taken into account as a process that seems makes the patient experience a permanent feature in our everyday lives. At the same time, for health practitioners normalization of the practices that constitute the patient as virtual has long since happened, even if each and every individual patient emerges as a virtual entity before them, not every patient will share the same *virtuality*³³. It is because of this gap that the role of intermediary agents or translators receives a certain importance (in particular as agents of *civics*), which the current literature doesn't properly account for: This is mostly a communication problem between laymen (patients), experts (doctors), and meta-experts who study this kind of interaction (e.g. medical sociologists): The debate between meta-experts in *science studies* on the one hand and among laymen, legislators, and journalists on the other hand, seems often like a transmuted discourse in the conceptual sick-role framework and, thus, it seems to result that those engaged in medical concept formation conceive of medical practice as it has been between 1850 and 1950. At the same time: In this framework, patient activity is reduced to “consenting” with the doctor's diagnosis and cooperate with the therapy regime. In many regards and despite calls for patient empowerment, medical practice is still mostly physician-centered and/or (health-)care-administration-centered. It seems still mostly unfashionable among scholars and practitioners to associate themselves with patient-centered medical philosophies such as Karl Jaspers' or

³¹Osborne P. Wiggins, Michael Alan Schwartz “Science, humanism and the Nature of Medical Practice.” *Perspectives in Biology and Medicine* Vol. 28 (1985) : 331 – 361; Osborne P. Wiggins, Michael Alan Schwartz “Systems and the Structuring of Meaning: Contributions to a Biopsychosocial Medicine.” *AmJPsychiatry* Vol. 143 (1986) : 1213 – 1221.

³²Carl May „The Clinical Encounter and the Problem of Context“ *Sociology* 41 (2007): 29 – 45

Carl May, T. Finch „Implementation, embedding, and integration: an outline of Normalization Process Theory“, *Sociology* 43 (3/2009): 535-554

³³I use the notion *virtuality* to mean a special type of *positivity* (Foucault) that is produced in a conflation of hyperspecialization and hyperdifferentiation.

Lawrence Henderson's (both of which presented different ways of thinking from before 1950), just as it has become necessary to side with the biomechanical rather than the phenomenological model of the body³⁴: If scholars want to get research funding, they better stay with the herd. However, a few brave critics have laid bare the fact that the creation of medical manuals, such as the Diagnostic And Statistical Manual for Mental Illness (DSM), is largely influenced by debates between operational and phenomenological diagnostics that were all the rage in medical practice in the late nineteenth and early twentieth century. They have argued that, effectively, the prevalence of operational diagnostics today is derived from the teachings of a German named Emil Kraepelin (1856 – 1926) and that it was men like Jaspers who brought empirical study of patients back in the early 1900s, which led to a reformulation of psychiatry and medicine, a redistribution of rationalities from pitting reductive views of biomechanics versus phenomenology to integrative ideas³⁵. In short, there are no one-size-fits-all therapy schemes nor are there magic bullets. However, in having turned bureaucratic and share-holder inertia into the sole acceptable form of rationality in governing both modern health care and research funding, we have created an institutional push towards just such a kind of reductionism, when what we actually need is a pragmatic and pluralistic integration of all approaches³⁶.

Instead, the situation is becoming increasingly complicated. In the social scientific assessment of health care and medical practice, the original concept of the sick-role (Parsons 1951) has become transformed into the “managed-case role” which eventually resulted in the emergence of a focus in the so-called patient-governmentality³⁷. To entertain this thought, just a few examples:

- Many patients are forced, under the pressure of metaphors of “self-care” and “patient responsibility”³⁸, to become active participants in their own diagnosis and treatments by use of information technology. In reality, “therapeutic modes of thought”³⁹ spill

³⁴NC Andreasen “DSM and the death of phenomenology in America: an example of unintended consequences.” *Schizophr Bull* 33(2007): 108–112; James A.Marcum. “Biomechanical and phenomenological models of the body, the meaning of illness and the quality of care.” *Medicine, Health Care and Philosophy* Vol.7 (2004): 311 - 320

³⁵ S. Nassir Ghaemi „Nosologomania: DSM & Karl Jaspers' Critique of Kraepelin.“ *Philosophy, Ethics and Humanities in Medicine*, 4:10 (2009)

³⁶Ghaemi, S.Nassir “Pluralism in Psychiatry: Karl Jaspers on Science.” *Philosophy, Psychiatry & Psychology* Vol.14 (1/2007): 57 – 66; Marco Bischof, *Salutogenese*. (Klein Jasedow: Drachen. 2010)

³⁷Susan Pickard “The role of governmentality in the establishment, maintenance and demise of professional jurisdictions: the case of geriatric medicine“ *Sociology of Health and Illness* (2010); online first

³⁸Stewart J.Murray „Care and the self.“ *Philosophy, Ethics, and Humanities in Medicine* Vol.2, (6/2007)

³⁹Julie McLeod, Katie Wright “The Talking Cure in Everyday Life” *Sociology* Vol.43 (1/2009): 122 – 139

from the clinical encounter into our everyday lives (Habermas' trauma of the "invasion of the lifeworld" becomes medical⁴⁰). Once therapy-modes themselves become *virtualized* within biomedicine, so will the spill-over into forms of life-course constructions. However, patients simply are no experts and have never practiced and exercised "medical judgment". Therefore, we must ask whether they can make choices on their own, regarding the integration of health-increasing measures into their life-course; this begins with relatively simple questions (is a person's organism equipped to handle a vegan diet or not) to a patient's dilemma in the face of two therapy choices in the face of a potentially lethal illness. It is easy to steer patients onto care-pathways, when they are overwhelmed by this kind of expert information, while they cannot access or assess all the alternatives that may surround the options they are given. The spill-over from therapeutic modes of thought into other areas of life, the restructuring of these areas by pathways and trajectories affects children most of all⁴¹, and often predetermine their life-course and evict autonomy⁴².

- Doctors diagnose and treat patients they have never even met, using various forms of tele-medicine⁴³. Experts rely on medical imaging technology⁴⁴ that create artificial pictures that require interpretation rather than reproduce reality. However, we must ask whether the patient and his/her body that emerge "technologically" really provide an adequate representation of the patient, his/her condition, and his/her suffering.

- At the same time, this trend is preceded, prepared and proliferated by the "shaping of biomedicine as an information science"⁴⁵, which reconstructs the "intimacy" of the re-

⁴⁰See also: Frank Furedi *Therapy Culture: Cultivating Vulnerability in an Uncertain Age*. (London: Routledge, 2004)

⁴¹Danielle L.Fettes, Jane D. McLeod "Trajectories of Failure: The educational careers of children with Mental Health Problems." In: *American Journal of Sociology* Vol. 13 (3/2007): 653 – 701

⁴²Any "health care reform" that puts *care* up front and center will have to account for this. And without wanting to delve into politics, no political party seems to have a genuine concept that would help along this goal of promoting autonomy in care. Liberal and Conservatives are fighting the wrong kinds of battle – battles of ideologies, that are each off the mark to start with –, while the patients, particularly underage patients, are left behind.

⁴³Kari Dyb, Susan Halford "Placing Globalizing Technologies: Telemedicine and the making of difference." In: *Sociology* Vol. 43 (2/2009): 232 – 249; Grenville Hadley, M.Mars, "Postgraduate Medical Education in Paediatric Surgery: Videoconferencing — A Possible Solution for Africa?" in: *Pediatric Surgery International*, Vol. 24 (Feb/2008): 223-226; Jonathan Matusitz, Gerald-Mark Breen „E-Health: A New Kind of Telemedicine" in: *Social Work in Public Health*, Vol. 23 (1/2007): 95-113

⁴⁴William Safire "Visions for a new field of *Neuroethics*" in: *Neuroethics: Mapping the Field* (Washington, DC: Dana Press, 2002: 3 – 9); Joseph Dumit *Picturing Personhood*. (Cambridge: MIT Press 2004); Anne Beaulieu, "Images are not the (only) truth: Brain mapping, visual knowledge, and iconoclasm" *Science, Technology and Human Values* Vol. 27, (2002): 53 – 87

⁴⁵Timothy Lenoir "Shaping Biomedicine as an Information Science," *Proceedings of the 1998 Conference on the History and Heritage of Science Information Systems*, edited by Mary Ellen Bowden, Trudi Bellardo Hahn, and Robert V. Williams. (ASIS Monograph Series. Medford, NJ: Information Today, Inc., 1999: 27-4)

relationships between a) care-takers and care-receivers, and b) humans and machines⁴⁶ in new ways. *Medical informatics* is a discipline that increasingly infiltrates hospitals and proliferates the bureaucratization of treatment by replacing the doctor's trained eye with diagnostic software. Case-management based solemnly on *medical informatics* reduces individual patients to bureaucratic units that are processed via software and assigned case-managers, medication, hospital slots, and, of course, bills. This process has been called – quite adequately, I might add – *informatization* for general purposes by Jos De Mul⁴⁷, and adapted for medicine by Brown&Webster⁴⁸. However, this process of turning medico-social ontology from patients into case-files is anything but a recent invention, if we are to read Berg/Harterink correctly⁴⁹.

These case studies emphasize the existence of the two underlying trends than can be analytically isolated and which unite these supposedly unrelated examples, which are in turn studied individually by different(iated) kinds of experts in sociology, anthropology, history, and philosophy: *Hyperspecialization* and *hyperuniversalization*. Together, these two trends form the process of increasing *virtualization*. As a corollary, the “managed case” in modern medicine and biomedical science is turning into the contemporary standard of our human condition, beginning with the fact that every person diagnosed with a pathological state of any kind does no longer simply occupy a sick-role, but becomes a case-file and thereby realized, reproduced, and reified as a *virtual patient*.

⁴⁶Maggie Mort, Andrew Smith “Beyond Information. Intimate Relations in Sociotechnical Practice.” In: *Sociology* Vol. 43 (2/2009): 215 – 231

⁴⁷Jus De Mul “The Informatization of the Worldview:.” In: *Information, Communication and Society* Vol.2, (1999): 69 - 94

⁴⁸Nik Brown, Andrew Webster *New Medical Technologies and Society*. (Cambridge, UK: Polity, 2004)

⁴⁹Mark Berg, Paul Harterink “Embodying Patient Records: Records and Bodies in Early 20th century US medical practice.” *Body&Society* Vol. 10, (2004): 13 – 41

IV. Digital Inequality and Health Care

It is an inescapable fact that Information and Communication Technology (ICT) is now present in almost every aspect of social life, from the dating game to the labor market, governance or shopping. With regard to its being part of the process of *virtualization*⁵⁰, it has also been subject of diverse discussion that not every member of society has been successfully integrated to participating in the *Information Society*⁵¹. Some researchers busy with studying this phenomenon in view of classic inequality are prone to stake claims such as the following ones:

- a) Those who “fall over the edge” are increasingly isolated and subject to this new form of *digital inequality*.
- b) However, this emergence of a *digital divide* does not affect (or create) new groups or classes of people who suffer inequalities; instead it only deepens already existing social division.

As a consequence of these ideas, we can conclude that in the realm of (health) care, just as in other sectors of life, the *digital divide* does not *become* a new social reality and social problem we are struggling to resolve. In short, digital inequality *is* affecting adequate access to care and medical treatment for those who have already been suffering from other forms of inequality (or, in other words, *digitalization* further excludes the already excluded).

⁵⁰ It should be made clear that, indeed, *virtualization* is not entirely a new process. While some may argue that “the virtual” is a result of modern information and communication technology, therefore, result of the latter half of the twentieth century, others such as Peter Sloterdijk or Sybille Kraemer have considered different accounts. Sloterdijk argues that “the virtual” has a 2400 year long history, whereas Kraemer discusses *virtualization* with regard to a medial transformation from language theory deriving from the Lutheran reformation, meaning the fact that for the prereformation world, the body of Christ and the consecrated wafer were considered to be (ontologically) identical, whereas the reformists introduced the idea of representation into the celebration of the communion. For the present purpose, my argument is that *virtualization* is a process deriving from the combination of hyperuniversalization and hyperdifferentiation (or hyperspecialization) in the social organization of professional knowledge production and the translation systems between lay-expert discourses. This can factually be observed since at least around the end of the 18th century. Nonetheless, in the present essay, we are busy with the contemporary effects of this process. We need to be reminded (against the standard account), however, of the fact that *virtualization* accounts for the transformations and innovations in information technology more so than the other way round. In other words, a technology such as the internet did not give birth to information society. See: Peter Sloterdijk *Sphaeren I*. (Frankfurt aM: Suhrkamp, 1998); Sybille Kraemer “Sprache - Stimme - Schrift. Sieben Gedanken über Performativität als Medialität” (Uwe Wirth (Hrsg.), Performanz, Frankfurt am Main: Suhrkamp 2002, S. 323-346)

⁵¹ Mark Warschauer. *Technology and Social Inclusion: Rethinking the Digital Divide*. (Cambridge, MA: MIT Press. 2003); Hiroshi Ono, Madeleine Zavodny “Gender and the Internet.” In: *Social Science Quarterly* 84:111–21; Donna L. Hoffman, Thomas P. Novak “Bridging the Digital Divide: The Impact of Race on Computer Access and Internet Use.” in: *Science* 280 (1998):390–91; Robert W. Fairlie “Race and the Digital Divide”. *Contributions to Economic Analysis & Policy* 3, (2004): Article 15 Retrieved May 4th, 2008 at: <http://www.bepress.com/bejeap/contributions/vol3/iss1/art15>; Matthew S. Eastin, Robert LaRose. “Internet Self-Efficacy and the Psychology of the Digital Divide.” in: *Journal of Computer-Mediated Communications* 6, (2000). Retrieved May 4th, 2008 at: <http://jcmc.indiana.edu/vol6/issue1/eastin.html>; see also: Ulrich Beck *Power in the Global Age: A New Global Political Economy*. (Cambridge: Polity Press. 2006)

In a tentative definition, the *digital divide* represents the division between people with access to and practical knowledge about modern technology, specifically technology categorized as *information technology* (IT) and the internet, and people without access to this technology or access to knowledge about it. With regard to health care and other aspects of social justice, we should additionally distinguish between the globalist and the nationalist perspective – which the literature sometimes fails to do, particularly in those studies suggesting that the *digital divide* refers mostly to the same old same old “first world-third world divide”. In the global perspective the difference between developed and developing nations in regard to IT access is immense. In the national perspective, the term *digital divide* is being used to describe differences in the availability of Internet access and information technology (IT) distribution between rural and urban areas in the US. However, it also refers to a division in competence to use information technology or to understand the organization of information according to IT principles. For a variety of reasons, this latter version of the gap is widening on a national level, even though many commentators appealing to the wider public tend to present the social inequalities that rise from the *digital divide* from the global point of view (playing along with the good old Western World versus Third World narrative), while downplaying the division between employees in traditional economies and *digital natives* in the US as more of a minor cultural division rather than a problem of social justice.

In light of the actual and more specialized research literature, we can assert that poverty and social class are issues that are profoundly affected by the *digital divide* even *within* most developed of nations. In sociological theory, effective descriptions for the emergence of such gaps are covered by the theories of access to different forms of non-economic *capital* following in the footsteps of the sociology of Pierre Bourdieu⁵². In this regard, access to health care is increasingly regulated by the ability to navigate the “digital worlds of health”. At the same time, access to other realms of social life, including access to the labor market, are also increasingly regulated by digital/information techniques. More importantly, though, access to these spheres and, particularly to jobs, requires *biological* or *health capital*:

The standardized ability to pay attention in psycho-physiologically designed assessment tests, passing a drug screening, etc. Respectively, knowledge about what kind of health indicators are required to gain access to the (academic) job-market, and how to “obtain” and “manage” these digitally produced and stored indicators, is another bolt in the construct of the digital divide. The consequence of such an account, which the current literature implicitly suggests,

⁵² Pierre Bourdieu “The Forms of Capital.” in: *Handbook of Theory and Research in the Sociology of Education*, edited by J. C. Richardson. (New York: Greenwood. 1986: 241–58)

is the postulate that members of the “lower social class” or of “underprivileged and marginalized groups” have little to no access to acquire certain traits, habits or information necessary to accomplish a rise in status, income class or livelihood – in short: they are deprived of access to participation in democratic society and its civil sphere..

In the case of health care itself, the problem lies in the fact that information that is necessary to make “informed decisions” can often only and exclusively be obtained *online*. Those who do not have access to the internet or lack IT competency are deprived of imperative information to secure participation in civic life in general, or make informed decisions regarding their health&care in particular. It is even more difficult for children, whose parents belong to a lower social class, to gain knowledge to command *information technology*. These parents will be lacking this kind of knowledge to use for their own good nor can they pass it on. Possessing this command, according to the Bourdieu-style of class-theory, is a necessary form of capital. To *command* a technology entails more than fleeting acquaintance with the technology, and only the commanding type of competency would enable a person to obtain *specific* information⁵³. If we consider the fact that many children from the “lower classes” also suffer from destructive life-style disorders (obesity, ADHD, &c.), if we also consider the position that an increasing amount of knowledge about therapy alternatives, programs, advise, exchange between parents or interested groups, and so forth, occurs online, it stands to reason that parents from a lower social class will not be able to access this kind of knowledge nor will their children be *enabled* to do so in later life. However, it is common knowledge that destructive behavior disorders are a) on the rise and b) not restricted to children and adolescents.

In some regards, I feel that the highly impressive arguments of normalization process theory, with Carl May at the head, do not reflect this dimension of social equality and justice as

⁵³Workplace requirements have reached a new level in “media-multitasking”. Most of us seem used to correlating our activities on a cell-phone while surfing the internet and downloading data on a PDA. However, we must learn these routines to successfully handle this variety of tasks. The learning process for such habitual routines is fairly time-consuming and gets harder with the increased age of the learner. Therefore, we have to think of another problem than mere class status, such as the problem of age: Elderly people do not adjust with ease to the swift changes in technology that we have seen over the past ten years. The two major problems they are facing, even when they are presented with access is a) their own fear or resentment and b) a form of “technological illiteracy”. Numerous studies show that reading web-content does require a multitude of learned skills. If a person is not educated to use these cultural techniques at an early stage, it will make the learning process harder and longer (Eszter Hargittai, ., [„Cognitive Ability and Internet Use Among Older Adults.“](#) *Poetics*. (Journal of Empirical Research on Culture, the Media and the Arts) 34 [4/2006]: 236-249; Eszter Hargittai, A. Hinnant. [„Digital Inequality: Differences in Young Adults' Use of the Internet.“](#) *Communication Research*. 35 [5/2008]:602-621). The *symbolic-capital* theory applies in this case, too. Consider the following analogy: Buying into a fledgling market requires a minimum amount of start-up capital. Once a market has gained momentum, it becomes much more difficult and requires an ever higher margin of investment to buy into it. The same with IT. If a person has not grown up within the development of the technology, it will require more effort and more accumulation of *symbolic capital* to acquire the necessary knowledge.

adequately as they probably should. And perhaps therein lies the tension between normativity and normalization⁵⁴, which makes the normalization of *informatized health care* and the form of the *virtual patient* turn into a double-edged sort: the normalization of the *virtual patient* as the “only” type of possible patient experience, also produces further exclusion for those who lack the (forms of) capital to participate in the *virtual experience*. And with regard to those who need care, this exclusion affects those who are already weakened, suffering, and in need of protection to begin with children, elderly people, people with disabilities, chronically sick, veterans.

With regard to health care, we could cite several examples, exceeding those about mere acquisition for information to be able to make good choices. Merely consider the following two examples:

An elderly person required to employ a complex pharmacological regime to herself might need to consult the written instructions frequently to prevent a confusion of medications, dosage, &c., or watch out for counter-indications and side-effects. However, in order to save production costs, the producers of medications may decide to provide this kind of information online and no longer print these instructions. Also, more and more measurements can be taken with self-measurement kits, such as sugar-level counters for diabetes patients. The technological apparatus to take those measurements will be designed with an information access infrastructure that resembles the infra-structure common to ICT used in hospitals. It would not be very cost-effective to produce several different types of machines.

In other words, the social *digital inequality* will replicate itself in health care and widen the gap further. We must bridge the digital divide, for the use of Information and Communication Technology (ICT) has become a necessity not only for participation in the labor market, or for political and social participation, in the form of access to certain markets, as well as government services. ICT competence is a necessary skill to make informed decisions when navigating the health care system or choosing between alternatives of action that affect that health-related quality of life (HrQoL) form children and adolescents.

An issue of increasing importance lies in consumer empowerment and, subsequently, health care consumer empowerment. Spreading information about health care products, therapy alternatives, health programs &c. has become a more difficult though the processes of *virtualization* and the increasing *digital divide*. For example, generic medical products, which members of lower income classes might be able to afford over brand products are often available

⁵⁴Dianna Taylor “Normativity and Normalization” *Foucault Studies* Vol.. 7 (2009): 45 – 63

through internet sources only. Studies have shown, like an exemplary one by Rains⁵⁵, that internet access and use can be positively correlated with personal health-care. Specifically access to newest broadband access in correlation with age and living in an urban area would contribute to personal health care as a factor. In that regard, the promotion of personal health-care is negatively affected through the existence of *digital inequality*. On the other hand, positive health-care effects increase one chances in social and economic participation. Enabling access to *e-health* is therefore a crucial factor to reduce the effects of *digital inequality*. Matusitz and Breen⁵⁶ discuss the wide range that the idea of *e-health* covers: They assume that an increasing number of health-care issues is relocated to the web. A development that will only increase *digital inequality*. Subsequently, the growing lack of actual dialogue between patient and doctor is in itself turning problematic⁵⁷. Those on the down-side of *digital inequality* in health-care issues are excluded from access to new developments in treatments, from comparative resources and experience sharing within patient groups. Not to mention the fact that knowledge about law-suits against the pharmacological industry for medication fraud or similar cases is often distributed via the internet.

All of these aspects play an increased role in modern health-care and also reformulate the question of citizens as consumers: Social participation has transformed in being defined some large part into participation in consumption, and social theory and analysis have long since reacted to this development. Therefore, theory has it, respectively, that in a global political economy that is increasingly dominated by so-called *multinational companies*, the remaining counter-power, as Ulrich Beck⁵⁸ suggests, lies not so much in the hands of national governments, but in the hands of the consumers themselves. It is, after all, the consumer who

⁵⁵Stephen A. Rains "Health at High Speed: Broadband Internet Access, Health Communication, and the Digital Divide." *Communication Research*, Vol. 35 (3/Jun/2008): 283-297

⁵⁶Jonathan Matusitz, Gerald-Mark Breen „E-Health: A New Kind of Telemedicine” in: *Social Work in Public Health*, Vol. 23 (1/2007): 95-113

⁵⁷Leading to the question, “Who translates?”, reinforcing the need for lifting the status and recognition, and improving the education opportunities of intermediary agents, such as (in particular) nurses.

⁵⁸Ulrich Beck *Power in the Global Age: A New Global Political Economy*. (Cambridge: Polity Press. 2006); also additional perspectives in: Nicholas Abercrombie, , “Authority and consumer society”, (Keat, R., Whiteley, N. and Abercrombie, N. (eds.), *The Authority of the Consumer* London: Routledge, 1994: 43-57); Marek Korczynski “The Mystery Consumer” *Sociology* Vol. 43 (5/2009): 952 – 967; Milton Friedman “A positive approach to organized consumer action: the boycott as an alternative to the boycott” *Journal Consumer Policy*, Vol. 19 (1996): 439-51; Yiannis Gabriel, Tim Lang *The Unmanageable Consumer: Contemporary Consumption and its Fragmentation* London:Sage (1995); Steven H. Lopez “Workers, Managers and Customers: Triangles of Power in Work Communities” *Work and Occupation* Vol. 37 (2010): 251 – 271 ; Janice Denegri-Nott, et al “Mapping Consumer Power” *European Journal of Marketing* Vol. 40 (9-10/2006) : 950 – 971.

Gabriel/Lang with Anne-Marie Mol (*The body multiple*. [Chapel Hill, NC: Duke UP, 2002]) makes us rethink the process of fragmentation of the modes of “being a consumer” and the modes of “being a patient” as potentially interrelated or as derived from the same conditions of possibility (or historic apriori [Foucault]).

has the final decision which products (including medical and care services) will be bought or not. The only currency consumers have in order to assume and control this power is information⁵⁹. This fact bestows national governments primarily with the role of making certain that consumers can attain and distribute this kind of information about health care and public health at the same time. Creating access to ICTs for everybody, and bridging the *digital divide*, is subsequently *the* civic task that modern states have to fulfill, if we want to restore or maintain the democratic power of the people. This type of maintenance used to be defined under the term *civics*. In our age and time, when knowledge about our health and our biology is readily available while the range of products, services and regimens that intervene in our biological organism increases, civics has to take on a new turn and become *biocivics*. Embedding *biocivics* in civil society is, perhaps, the only way to account for the effects of exclusion that *virtualization* creates – effects that are produced by the current forms of governmentality and normalization. Scholars like Susan Pickard and Carl May theorize these forms themselves quite adequately. However, normalization process theorists, in particular, are underestimating the need to account for equality and justice in proper measure. Governmentality theorists fare hardly better. Their focus on the interplay between governmentality and resistance and the forms of subjectivities sometimes derails their discussions and leads them away from basic problems of access and exclusion in (health) care, patient experience, and medical practice in general, and their virtual form in particular. If normalization and governmentality theorists were to follow Foucault more strictly, they would turn her focus not on the subjectivities themselves (and the [alternate] forms of the resistance they provide), instead they would focus even more deeply on the practices and positivities⁶⁰ that constitute them. In other words, the road to social justice means to account for the effects of *virtualization* of health care by educating the *citizens* to understand their biology, navigate health care information, and become enabled & empowered consumers. Biocivics is, therefore, a crucial aspect of social justice in the 21st century.

⁵⁹ Manuel Castells *Communication Power* (Oxford: Oxford UP, 2009); Yochai Benkler *Wealth of Networks* (New Haven: Yale UP, 2007)

⁶⁰Perhaps it is helpful to note that I view Foucault's *positivities* to be of similar design as Weberian *historic individuals*. I am not aware that this notion has been properly discussed, let alone operationalized.

V. *Biocivics: A complex-systems account for knowledge/legal/bureaucratic regimes in public health.*

The 21st century concept of citizenship has become *biological*. Regimes of truth and knowledge production have to account for new concepts such as the *neuro-chemical gaze* (Nikolas Rose), *biotechnologies of the self* (Stuart Murray), or *biopolitics* (Paul Rabinow). However, academic discussions concerning the *biological citizen* (Nikolas Rose, Aihwa Ong) and the virtualization of the patient experience have been lacking accounts of a) the effect of the information order problem, long-running conceptual histories and semantics in actual decision-making (semantic agency), b) the complexity of relations between different individual and collective actors (complex systems), and c) the aspect that biological citizenship is necessarily a concept of active citizenship, which means that it is not a natural kind but a continuous process of becoming that requires learning and education (civics or *biocivics*), d) organizational processes that pre-structure contingencies and options in situations of actual decision and countermand active citizenship and biological autonomy.

Knowledge regimes determine processes of decision-making in legislative debates, health care bureaucracies, diagnostic/therapeutic consultations, or everyday situations involving individual health and well-being. They affect and produce lifestyles, nosologies (classifications of health/illness), bureaucratic procedures and research programs. New research into health-care, doctor/caregiver-patient relations, and biomedical research must take complex systems research into account as well as conceptual history, the problems of the layman-expert gap, and the semantic properties of agency. It must account for macro-trends, such *hyperspecialization*, *universalization*, or *virtualization* on the one hand, and micro-level decisions and effects on the other hand, before mid-range policies, practices and institutions can become a goal for research towards improvement. In practical application, health care reforms must account for the causes and effects of *virtualization* in health care politics and public health that govern biomedical research, the health-care system and health-care education. Instead of proliferating *virtualization* any further, we need to “bring the patient and the doctor back in”, and help, above all, the intermediary agents, such as nurses, to achieve the status and education they deserve in enabling the successful communication between administration, doctors and patients. This is what we need to think about a critical *medicine studies* program for. We need to understand the “properties” of agency in decision-making in complex health-care systems and legislative processes. And we are not nearly there yet. We need an investigation of the processes and social structures of hyperspecialization and hypergeneralization that continue to

govern the emergence of the *virtual* patient and the managed case. It follows that the *virtual patient* must be seen as a medium of social change in modern health systems, both on the institutional and the individual level. These effects must be highlighted and made transparent in light of their origin and consequences for processes of decision-making between doctors and patients, within bureaucracies and, most importantly, in policy-making. Finally, we need to open new roads for collaboration in the production of a basis for future research, reform of public health programs and health education(*biocivics*), lifestyle improvement, such as therapeutic intervention on ADHD, obesity, among others.

VI. Conclusion

This discussion involves the ethics of decision-making in public health and therapeutic regimes between pharmacocentrism and integrative whole-systems perspectives. I am arguing for a pragmatic integrated approach in public debates, policy-making, and the doctor-patient situation, accounting for different environmental influences and individual biological properties of patients. We need a more extensive analysis of the effects that political debates, health-care economics (e.g. consumerism in health care), and *virtualization* have on health-care, public health, and the bureaucracies and legislation that affect patients and care-givers in light of the policy-decisions that follow.

The effects of the ongoing process of *virtualization* remain a result of

- a) *hyperspecialization*, a co-evolution of both, the biomedical profession, modern knowledge-based economy and politics, and the professions that study scientific development, and
- b) *universalization*, the trend to create categories for diagnosis, therapy, and scientific study that can be easily integrated into bureaucratic processes and the advancement in information technology.

Virtualization is the process that disciplines members of the medical and scientific community, public health legislation, and patients alike, to become fit for the information- and knowledge-based economy of our times. As a consequence, *virtualization* does not simply change medical practice, it changes the way we think about the human condition. We are under threat to lose sight of actual patients and, as a consequence, dehumanize health-care in the process. Technological and bureaucratic advances are meant to work for us as patients, we are supposed to be the ends of the system not its means. If we fail to make the impressive innovations that led to *virtualization* work for us, we will end up as the means that exist to maintain the ongoing process of *virtualization*.