

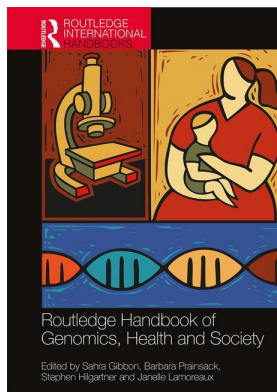
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### **Biomedicalization in the Postgenomic Age**

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# Biomedicalization in the Postgenomic Age

*Catherine Bliss*

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## Introduction

In the last quarter century, medicine has acquired a technological and scientific makeover just as it has encroached into ever more aspects of human life. Today, it is often referred to as “biomedicine,” connoting the turn toward the burgeoning fields of genomics, bioengineering, biotechnology, and biostatistics. These transformations have generated new ramifications of its growing influence, what researchers now refer to as “biomedicalization.”

This chapter introduces the concept of biomedicalization, presenting some major developments in social theory and research. It opens with a look at what biomedicalization is and how it relates to other social processes, such as geneticization and pharmaceuticalization. It then discusses emerging developments in molecular science and the characterization of risk, emerging avenues in social movements and identity politics, and the rise of consumer genomics. The chapter concludes with a look at how biomedicalization entwines with broader forms of capitalism and sociality in the New Millennium.

## What is biomedicalization?

“Biomedicalization” has been used to explain a wide gamut of social phenomena, from specific diseases such as HIV and cardiovascular disease to overarching conditions such as mental and sexual health, as well as to life processes such as aging and dying and social characteristics such as race, gender, and sexuality. Researchers examining these phenomena have noticed the ways in which biomedicine has come to define them, casting such phenomena with a bioscientific imprimatur.

The term “medicalization” was first introduced in the early 1970s to characterize the social process by which medicine increases its jurisdiction, entering into formerly nonmedical domains of life (Conrad 1975; Zola 1972). Theorists at the time trained their attention on the dominance of the medical profession, encouragement by social movements and patient advocacy groups, and changing institutional or organizational structures that supported the increasing reach of medicine. Yet by the turn of the Millennium, scholars were finding that medical authority wasn’t what it used to be, medicine itself was again restructuring in critical ways, and

the forms that health organizing was taking were also changing drastically (Conrad 1992, Starr 2008). Due to government cost control measures and the success of social movements to create patient-based and holistic healthcare, the professional dominance of doctors was rapidly eroding. A corporate brand of managed care was taking the place of self-administered physicians networks. The pharmaceutical industry rushed in to sell drugs directly to managed care organizations and to patients themselves. Third-party payers also grew in influence, assuming a gatekeeping role in healthcare (Prainsack, this volume).

The late 1990s was a critical time for medicine, as the world braced itself for the first mapping of the human genome. The Human Genome Project published a draft map in 2000, and medicine underwent a paradigm shift, becoming rationalized by bioscientific interests and aims (Clarke et al. 2010). A substantial biotechnology industry arose, replete with new, closer academic–industry relations and a growing market of direct-to-consumer goods.

One major aspect of the new bioscientific medicalization, what Clarke et al. (2003: 162) summarize as “the increasingly complex, multisited, multidirectional processes of medicalisation that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine,” is economic restructuring toward the consolidation of a “biomedical technoservice complex.” This new system is characterized by multinational corporations and privatized rather than state-funded research and healthcare. Again, managed care systems have replaced physician-dominated systems. Meanwhile, increases in fee-for-service options and the devolution of healthcare management to individual patients, as well as new population-based practices that rely on new concepts of identity, have created a uniquely stratified form of medicalization.

A second aspect of biomedicalization is a concerted focus on health, risk, and surveillance. Health has become a moral imperative, something individuals must work toward. Governments, medical organizations, and individuals themselves constantly monitor risks, and they do so in terms of genetic diagnoses and molecular categorizations. As Clarke et al. (2003: 172) note, “it is impossible not to be ‘at risk.’”

Third, biomedicalization is characterized by a “technoscientization” of biomedicine, that is, a rationalization by technology and science at the same time. Processes and systems are computerized and standardized by new technologies and scientific classification systems. Healthcare is driven by evidence-based biomedicine, which is itself characterized by statistical reasoning and molecular science. A host of “Omic” sciences prevail, encouraging biological engineering “from the inside out” (Clarke et al. 2003: 176). Healthcare is delivered by way of electronic record systems, digitized biotechnologies, and bioengineered applications.

Fourth, biomedicalization works by way of new transformations of information and the production and distribution of knowledges. Biomedicine dominates the media, where it dispels alternative notions of health and wellbeing and alternative systems of knowledge. Responsibility for one’s health is cast as an individual problem that is to be addressed with consumer applications. A range of cottage industries has cropped up offering consumers DIY (Do-It-Yourself) goods and services, while health gurus and high-profile medical experts have encouraged patients to go online, self-diagnose, and purchase products. At the same time, pharmaceutical commercials and news of clinical trials trump alternative and complementary medicine, now joining with healthcare professionals and patient movements to popularize genetic tests and cures (Löwy, this volume).

Finally, biomedicalization entails a transformation of bodies and identities. Biomedicalization is no longer about controlling a pathological entity, but rather hinges on customizing bodies to be the best they can be. There are two fundamental rhetorics, that of choice and lifestyle optimization. Individuals are pressed to opt for healthy behaviors and habits in their everyday

lives, and to use biotechnologies to constantly monitor their improvement from moment to moment, in real time. Norms have multiplied such that there is no longer a singular definition of what it is to be “normal.” A plethora of identities have emerged, forged through the interaction with biotechnology and new medical classifications. Increasingly, identity is cast in genetic terms, and it is done so amid a global network that has important international ramifications (see Jingfeng in this volume).

Medicalization theorists have debated whether these transformations warrant a shift in terminology (Conrad 2005; Rose 2007). Still, all agree that where medicalization occurs, it is unique in how it links up with processes like geneticization, molecularization, and pharmaceuticalization, the processes by which reductionist genetic explanations are used to describe differences between individual and group traits and behaviors (Lippman 1991), molecular models advance in science and society (Chadevarian and Kamminga 1998), and the way that conditions are transformed into opportunities for pharmacological interventions (Williams et al. 2011). Biomedicalization increasingly involves the redefinition of characteristics and conditions as inherently found in one’s DNA code and thus knowable and treatable by biomedicine, propels molecular models forward in the various fields and subfields of biomedicine as well as in healthcare and society, and bolsters pharmacological hegemony in the basic structures of bioscience and health delivery systems, often leading to an individualization of intervention and a depoliticization of care (Bell and Figert 2015).

### From genetics to genomics: new avenues in risk

Genetics has been a leading science for over a century, emerging soon after Darwin published *The Origin of Species* in 1859 and gaining ascendancy in the twentieth century. In the late 1970s, geneticists discovered ways to splice and recombine genomes, and the new science of genomics was born. Since then, scientists have delved into the human genome looking for genes responsible for common chronic illnesses and traits that are relevant to everyone. Still, today genomics has just barely begun to enter the clinic, and has done so more in terms of conversations about potential susceptibilities than actual drugs and diagnostics.

Risk has become a central motif in light of these changes (Tulloch and Lupton 2003). Though genetics also dealt in susceptibilities in its testing for carrier status of single-gene diseases, genomics’ focus on multifactorial matters has created a form of biomedicine in which every marker provides some degree of risk status (Rose 2009). Now it is the responsibility of each and every individual to learn about their susceptibilities, to manage them, and optimize their health and wellness with this information.

Some analysts have hailed the ushering in of a Risk Society, a system in which all of our social institutions enforce surveillance and self-surveillance (Adam et al. 2000). However, many note that it is the individual and the individual body that is the main conduit for risk management in the genome age (Lemke 2015). Neoliberal ideologies of individuality and self-government combine with a depoliticized form of public health, devolving responsibility from the state to local experts and lay citizens (Tulloch and Lupton 2003; Prainsack, this volume). The state is still interested in maximizing human potential for state interests, but this is envisioned in terms of a multiplicity of norms by which each and every individual must judge her own capacity and determine the best way to optimize it (Clarke et al. 2010). Individuals are trained to read their own bodies in light of ever refined genomic population affiliations (Rabinow and Rose 2006). Again, the focus is not on clinical branding or cordoning off diseased populations from the healthy as it has been in the past, but rather self-analysis toward self-imposed regiments based on evidence-based biomedical data (Niewöhner 2013). Managing risk requires a “new

prudentialism” involving analysis of the complete array of lifestyle choices available to an individual (Nadesan 2010). It requires both buying and buying into a certain way of life that can promote optimal health and wellbeing.

Time is compressed in that markers of the past, the innate traits passed down via one’s ancestry become a matter for present-day manipulation in the interests of creating a healthful future (Tutton 2014). Living to one’s fullest potential requires gathering all the probabilistic data out there and using it to manage, modify, and mutate, not so much as to stabilize in a new form but rather to adapt the past toward a future good (Rose 2009).

Yet, these new avenues in risk create social inequality. Biopower, power’s “capillary form of existence, the point where power reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives” (Foucault and Gordon 1980: 39), has become all encompassing. The regulatory dimension of biopower, the biopolitics of the population, looms larger than ever in the form of global genomic sequencing projects, including state-run projects that attempt to collect the DNA of all citizens in a given body politic, and genomic public health initiatives designed to replace social epidemiological ones (Rapp 2013; Shostak 2013). Furthermore, governments use biomedicine to engage in “dividing practices” in which certain populations are classified as different and in need of specific forms of treatment, and biomedicine relies on state taxonomies to conduct research and administer and deliver healthcare (Braun et al. 2007). In liberal western democracies, race is one dominant mode of classification. Engagement and care is also gendered and distributed unevenly according to sexual orientation and socioeconomic status (Happe 2013).

Biopower’s disciplinary dimension, the anatomo-politics of the body, is equally imposing as internal control over bodily functions throughout daily life becomes paramount to “living the good life” and “being a good citizen.” Eugenics reappears in today’s biomedicalized form of citizenship, or “biological citizenship” (Heinemann and Lemke 2015; Petryna 2013). The sharp increase in pharmaceutical consumption, body sculpting, and plastic surgeries, means that social norms are completely internalized and branded into the body (Dumit 2012; Menon 2017). As Mamo and Fosket (2009: 927) argue, “bodies are not born; bodies are made.” People view themselves as projects to be eternally worked at. In line with the immanent nature of risk management, bodies are seen as always already incomplete. The focus of self-making is less on disease status than on health and wellness in the moment, thus biomedical discipline reaches into every aspect of life leaving nothing to spare.

Biomedical influence and corollary ills such as genetic determinism, molecular supremacy, and pharmaceutical dominance may not be entirely complete (Franklin and Roberts 2006; Lock 2008). What scholars are calling “postgenomic science,” fields like epigenetics (the study of noncoding DNA sequences and their regulation of genes) and gene-environment interactions science, including social genomics (the study of DNA’s role in social behavior and outcomes), conceive of genes as being situated in and responsive to their environments (Meloni 2015). They promote “a break from the gene-centrism and genetic reductionism of the genomic age...an emphasis on complexity, indeterminacy, and gene-environment interactions” (Richardson and Stevens 2015). Moreover, studies of conditions undergoing geneticization have found that many conditions do not end up defined in molecular terms or treated by pharmacological means (Gibbon and Novas 2007; Shostak, Conrad, Horwitz 2008). Studies of genetic testing also have shown that people often question the predictivity of tests, and rely on other sources of knowledge to determine paths forward (Hedgecoe 2009). As Clarke et al. (2010: 28) argue, biomedicalization “is punctuated by contradictions and complications of power, knowledge and social action.”

But while the new focus on genes in context is altering biomedicine's course, and creating new meaning around genomic causality, "next generation" sequencing projects, such as whole genome sequencing projects and multinational gene-environment sequencing projects, continue to be racialized (M'Charek, Schramm, and Skinner 2014; Shim et al. 2015). The pharmaceutical industry has delivered race-based medicine to populations around the world while continuing its practice of stratifying by gender (Annandale and Hammarström 2015; Inda 2016; Kahn 2013; Pollock 2012). Biotechnology is increasingly focused on behavioral traits in ways that encourage eugenics in all areas of life (Bliss 2017; Reardon 2011).

A recent surge in gene-editing technology has only compounded these trends, making the advent of "designer babies" a fast-approaching reality. In 2015, researchers from around the world descended upon the U.S. National Academy of Science to decide whether to prohibit gene editing from being applied to the human germline. While the scientists present agreed to put a temporary moratorium on germline editing, only four government science bodies were represented, and no official policies were made. Currently, gene editing is unfolding unregulated in the global market, where startups dedicated to applying the technology to everything under the sun abound, thus it remains to be seen how conceptions and practices around risk will change in the new postgenomic climate (Ishii 2015).

### Identity and health activism

For centuries, medical knowledge has shaped the social categories of difference that make up the building blocks of who we are with public health drives, censuses, population controls, pronatalist policies, and eugenic strategies (Raman and Tutton 2009). But biomedicalization has brought the relationship between identity and biomedicine into a closer relationship than ever before (Clarke et al. 2010). Technoscience is changing identities in fundamental ways, as medicine is sold to the individual based on privately profiled information, and distributed through informatic networks connected to intricate research and health databases (Tepini and Leonelli, this volume). Pharmaceutical and biotechnology markets not only determine what tools are at hand in the crafting of new identities but also influence how patient advocacy organizations and other health groups produce a politics of health (Biehl 2013; Nguyen 2010).

As identity is reconstituted through the dominant goods and services available, race, gender, sexuality, and class is also biomedicalized (Duster 2007; Schramm et al. 2012). Markets are not only stratified in terms of participation and labor, but goods and services are also targeted at specific niches of the population thereby reifying social differences along identity lines (Epstein 2008). There is an intersectional dimension to this. People of varying class backgrounds are differentially gendered and raced, and vice versa, in the process of buying and selling reproductive services (Almeling 2011; Benjamin 2013; Waldby and Cooper 2008). "Categorical alignment," or the fusion of ascription and identification processes around hegemonic taxonomies has ensured that the dominant category sets used in biomedicine are realized in lay identities (Epstein 2008).

Bioscientists have also been shown to encourage the use of particular characterizations of human difference, even down to the level of taxonomy and label (Panofsky and Bliss 2017). Due to a specific rollout in American Public Health, and the directorial role of the United States in global genomics, all of the world's global genome projects since the turn of the century have classified according to U.S. federal racial standards (Bliss 2012). The field of genomics has not only adhered to these constructions, but the field's leaders have pushed for minority inclusion in genomic research with a heightened attention to racial identity (Reardon 2009; Montoya 2011; Smart et al. 2008). Bioscientists have gone so far as to market blackness or Latino-ness and

particular notions of diaspora through the rubric of DNA with tests and drugs aimed at particular groups (Fullwiley 2008; Lee, this volume; Nelson 2016).

Laypeople have equally fought to construct identity along such lines, and to have their constructions recognized and reflected in biomedicine, by creating and joining illness-based social movements, generating lay knowledge about their own medical conditions, and forging new communities based on illness identities (Brown 2013; Brown et al. 2011). They exchange information about their treatment options, participate in national fundraising events, and mobilize in support of relevant policies and initiatives (Klawiter 2008). Such health activism mobilizes research, and oftentimes researchers (Jasanoff 2011; Panofsky 2010). Political groups similarly mobilize grand-scale community health efforts through the proliferation of alternatives to racist and sexist research (Nelson 2016).

Indeed, a completely biomedicalized form of sociality, a “biosociality,” has sprung up in which people are organizing around their DNA code (Rabinow 1992: 244). Genetics-based health social movements have proliferated, demanding further biomedicalization (Clarke et al. 2009). Feedback loops form between health activism, research on human variation, and individuals’ own struggles to learn how to manage the array of “probabilities, predictions, and preventative interventions” arising from genomic knowledge (Rose 2009: 161).

Dovetailing with this is a global market of direct-to-consumer genetic tests with which people engage in a range of activities, including family planning, parenting, and political bargaining (Kelly et al., this volume). This market creates an apparatus of commodification and standardization around the categorical building blocks of identity that further essentialize traits and behaviors (Bliss 2017). The idea is for all humans to begin tailoring their lives to their genomes from day one, in a biomedicalized form of eugenics.

## Conclusion

In sum, biomedicalization is an analytic that helps us ascertain the major shifts in today’s social order around the expansion of biomedicine. Medicine is now molecularized, focused largely on genetic essences, and ubiquitous. It is a part of everyday life.

The key shifts this brings are around commodification and economic restructuring, the move from deviance or pathology to personal susceptibility and risk management or enhancement, technoscientization of all aspects of life, the knowledge economy and means of knowing about oneself, and identity formations. As such, the real power of biomedicalization is its ability to impact what people believe is good, logical, and right. Biomedical knowledge influences cultural and political struggles taking place around the world, and it is the basis with which bodies are perceived, interpreted, and understood. It is the zeitgeist of the New Millennium, a “new imaginary” for the globalizing world (Franklin 2003).

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