Health and personal responsibility in the context of neoliberalism: Cultivating alertness, autonomy and accountability through three contemporary health practices

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Abstract
This essay considers the shifting relationship between the concepts of “health” and “personal responsibility” by examining three contemporary health practices with significant social and political implications. First, this paper examines the advent of direct-to-consumer genetics, made possible in 1997 when the Food and Drug Administration relaxed standards regarding the direct advertising of pharmaceutical products to the public. Second, self-diagnosis questionnaires for mood disorders such as depression and anxiety are explored. Lastly, consideration is given to the institutional forms that ask patients to specify which medical interventions they would like to receive, or decline, in the event of childbirth and end-of-life care, respectively. Ultimately, this essay suggests that neoliberal policies and modes of thought call upon individuals to become certain kinds of health-subjects: subjects who are alert, autonomous and above all, accountable.

Key words: neoliberalism, responsibility, direct-to-consumer genetics, self-diagnosis, choice

Introduction
It is often said in cautionary tones that we have entered a new phase of economic and political order summed up by the term ‘neoliberalism.’ Within this order, free enterprise is considered beneficial in every corner and for all, and personal responsibility is perhaps the ultimate abiding value. Professions that were previously regarded as relatively independent from market dictates—notably the medical professions—can no longer be regarded as such: patients have become “clients” (or sometimes, “consumers”) and their physicians have become “providers.” Neoliberalism, according to Aihwa Ong (2006), fundamentally involves “a new relationship between government and knowledge through which governing activities are recast as nonpolitical and nonideological problems that need technical solutions” (p. 3). Health, a culturally contingent value and means for communicating social and personal worth, is an ideal vehicle for fortifying this form of governance. Sociologists of medicine since Foucault have recognized that health discourses do ideological work so effectively precisely because they do not appear to be doing any ideological work in the first place. Health discourses often circulate in such a way that they appear apolitical and value-free. After all, who would choose to be unhealthy? The choice to work toward health doesn’t seem to be a particularly political or value-laden choice. It might not even appear to be a “choice” in the first place. A second key feature of neoliberalism, as articulated by Davi Johnson (2008) in her work on biopower, is that it “works through and not against individual freedom. Instead of imposing restrictive edicts, [neoliberal] government works by constituting individuals as active citizen-agents and aligning the perceived interests of individuals with the interests of the state” (p. 149).

The proliferation of health discourses that emphasize personal agency and individual choice led sociologist Robert Crawford (1980, 2004, 2006) to coin the term “healthism,” which he defines as a phenomenon that involves the “striking moralization” of contemporary health practices. Given the emphasis on individual agency and empowerment within contemporary health discourses, it is reasonable to view the pursuit and performance of health as one of the primary means through which individuals demonstrate the control they have over their bodies and lives. As Monica Greco (1993) puts it, “the categories of health and illness have become vehicles for the self-production and exercise of subjectivities endowed with the faculties of choice and will” (p. 357).
In contrast to contemporary conceptualizations of health that emphasize the agency of individual patients, a dominant social critique of medicine in the 1970s and 1980s argued that the medical profession represented the preeminent form of expert authority and knowledge. Eliot Freidson (1970), who studied the structure of professions, said that medicine’s dominance stemmed in part from the fact that it was relatively free from market dictates when compared to other professions, and that it was for this reason that all other professions struggled to model themselves after medicine’s professional autonomy. The privileged position that medicine occupied was thought to reinforce its paternalism, and ultimately subjugate the agency of patients. The role of the patient, in many of these analyses, was highly circumscribed and the interaction between patients and physicians was conceived as unidirectional: the physician/expert dominates, the patient submits.

Whether such an intense period of medical dominance ever truly existed outside the scholarly literature is debatable, (Coburn, 2006) but it is nonetheless the case that the medical profession has undergone shifts that Peter Conrad (2007) describes as nothing short of profound. Few social critiques of medicine mobilize neoliberalism as a means for analyzing the shift toward linking health with responsibility and agency; likewise, few critiques of neoliberalism examine the impact that its policies and philosophies have had on the medical profession and the conceptualizations of health that it encourages. The deregulation, decentralization and general emphasis on individual responsibility that are hallmarks of neoliberal policies and modes of thought have led to reconfigured notions what it means to be “healthy,” what can and should be done in the pursuit of health, and who is ultimately responsible for promoting and securing health.

This essay will suggest that the reach of neoliberalism has extended into contemporary health practices considers the entailed social and political implications at play. To demonstrate this point, this essay considers three contemporary health practices and the discourses that circulate around them. These practices include: 1) the direct marketing of pharmaceutical products and services—in particular, genetic tests—to the public, 2) the proliferation of online self-diagnostic questionnaires for mental disorders, and 3) the institutional forms that enjoin patients to specify which medical interventions they prefer to receive, or decline, in the context of hospitalized birth and end-of-life care, respectively. These health practices were selected because they all emerged in roughly the same time period (the 1990s), they all strongly implicate the role of the patient in the management and outcomes of her own health care, and they are all forms of health-seeking that are taken up, more or less, freely.

**Deregulation, Direct-to-consumer genetics and dual responsibility**

With the and Food and Drug Administration Modernization Act of 1997, the United States became one of only two countries in the world that allows pharmaceutical companies to market their goods and services directly to the public. This was clearly a game-changer, both for the pharmaceutical industry and the medical profession at large. Up until 1997, Food and Drug Administration regulations prevented pharmaceutical companies from aiming their marketing efforts at any party other than physicians and healthcare professionals; advertisements were placed in medical journals, medical events were sponsored, and salespersons were sent to the offices of healthcare providers. Since the loosening of FDA regulations, the money that pharmaceutical companies spend marketing their products and services is now split down the middle, with one half spent on advertising to medical professionals, and the other half spent on advertising to patients or ‘consumers.’ Some championed the empowering effects that this loosening of regulations would have on consumers. A.F. Holmer, (1999) for instance, suggests that “[Direct-to-consumer-advertising] is an excellent way to meet the growing demand for medical information, empowering consumers by educating them about health conditions and possible treatments” (p. 380). While this ‘education’ does indeed seem to be reshaping healthcare, the conflation of ‘information’ with ‘empowerment’ merits unpacking.

The shift ushered in by DTCA has complicated questions of who is responsible for knowing what in the context of healthcare, and who is qualified to translate knowledge into action. Peter Conrad (1992, 2005), who helped to popularize the term “medicalization,” points out that while physicians still serve as gatekeepers when it comes to prescribing drugs, it is now the case that pharmaceutical companies exercise greater agency in defining what constitutes an ‘illness’ for which the prescribing of a drug is reasonable and desirable. Conrad says that this has led to “marketing diseases, and then selling drugs to treat those diseases.” Sometimes, as in the case of minoxidil (used to treat “androgenetic alopecia” or male-pattern baldness) the drug exists prior to the marketing of the disease, disorder, or malady that it is said to treat. Additionally, consumers have taken on a more agentive role in propelling forward the medicalization processes by which more and more ‘problems’ of daily life are folded into the jurisdiction of medicine.

Now, close to two decades into DTCA,
patients/consumers are accustomed to being introduced to, as well as seeking out, a range of new pharmaceutical products and services. With the growing emphasis on prevention, one of the more interesting services that patients might encounter, and have interest in, is direct-to-consumer genetic testing. These tests identify a range of genetic predispositions that a patient has, from breast cancer to sickle-cell anemia, and many other conditions both rare and commonplace. To undergo testing, an individual merely needs to swab a piece of cotton in the mouth and then send the sample to a specified laboratory for testing. Some time later, the consumer will receive a report about their genetic predispositions and risk factors. These tests are marketed, typically without any governmental regulation or oversight, to consumers in the form of television and radio advertisements, and increasingly, through internet-based media.

Like DTCA more generally, these tests are championed for their empowering effects, because ‘knowledge is power,’ and because knowledge is thought to be additionally empowering if it can be acquired without governmental oversight. This lack of governmental oversight is in fact one of the primary selling points for direct-to-consumer genetic tests. The tested individual’s information is kept private and is not available to health insurance companies who might use that information to justify the increase of premiums or termination of coverage. It’s hard to see this as anything but a benefit to patients/consumers. But beyond this, these tests are part of a larger trend toward the privatization and commercialization of health care services, and thus represent an important part of the neoliberal project. As David Harvey explains, “In so far as neoliberalism values market exchange as an ethic in itself, capable of acting as a guide to all human action, and substituting for all previously held ethical beliefs, it emphasizes the significance of contractual relations in the marketplace. It holds that the social good will be maximized by maximizing the frequency of market transactions, and it seeks to bring all human action in the domain of the market” (p. 3). While the privatization of genetic testing might well safeguard patients’ medical information, it is problematic to assume that all effects of privatization will be equally beneficial.

In addition to bringing yet another aspect of health (in this case, genetic risk) into the marketplace, direct-to-consumer genetic tests foreground several of the key values that help to constitute neoliberal modes of thought: individuation and autonomy (Rose, 1998). Genetic tests map, quantify, predict and manage the possible and probable future health outcomes, and do so in terms that are as individualized as possible; environmental and collective health risks and contingencies are not emphasized here. These testing services, taken up freely by the individual, impress upon her that her health subjectivity is highly individuated, bounded and autonomous and is thus a matter for which she is ultimately accountable.

These genetic testing services add a new dimension to the larger project of risk calculation and management that is considered a primary preoccupation of neoliberal governance. While many of the daily risks that individuals are exposed to are not necessarily completely within the scope of their control, (say, pollution or automobile collisions), people are still taught to be on the lookout for possible health risks and to actively mitigate those risks before they materialize. Direct-to-consumer genetic tests are specifically designed for this purpose, and they allow the user to demonstrate her responsibility in an era where responsibility and risk are intimately connected. The individual who actively seeks out knowledge of risk, in the name of mitigation and prevention, is often described as ‘becoming educated’ or ‘taking control’ of her own life. Along with this demonstration of education and active control, the test-taker also exhibits an ingrained sense of responsibility, both for herself and for others; she ‘owes’ it to herself to know all that can be known in order to secure health and she also owes it to those around her whose lives might be affected by her genetic inheritance.

As Novas and Rose (2000) explain, “When an illness or a pathology is thought of as genetic, it is no longer and individual matter. It has become familial, a matter of both family histories and potential family futures. In this way genetic thought induces ‘genetic responsibility’—it reshapes prudence and obligation, in relation to getting married, having children, pursuing a career and organizing one’s financial affairs” (p.486). In this way, genetic tests imply and reinforce a sense of dual responsibility. This dual responsibility is, in a sense, paradoxical. On the one hand, one’s health subjectivity is highly individuated, bounded and autonomous. It is for this reason that one is ultimately considered accountable for one’s own health. Yet on the other hand, an individual’s genetic risks implicate a range of others who merit consideration, which might imply that our health subjectivities aren’t so autonomous after all—they are bonded.

**Self-diagnosis questionnaires, depression, and knowledge production**

Self-administered questionnaires abound, particularly in the digital world, promising insight into a number of dimensions of the self including career aptitude, relational compatibility, intelligence quotient and so on. These questionnaires, despite having divergent foci, tend to be structurally similar. The user is
presented with a list of reflective questions that, after answering, will provide the user with information about the various categories to which she belongs, and where she falls in relation to other test takers. While these tests can be undertaken from the privacy of one’s home, this process of self-measurement has implications that extend beyond the realm of the individual test taker, especially when these self-diagnostic tests pertain to mental health disorders with few or no physically measurable symptoms.

While there exists various markers that divide and categorize individuals based on physically observable components of health-status, Foucault and his successors have discussed the various ways in which non-visible or otherwise unobservable markers of health-status—such as mental health—also function as dividing factors. But before this division can occur, these non-visible markers of health need to become calculable. That is to say, calculability precedes actionability. As Nikolas Rose has shown throughout his body of work, the technology through which non-visible markers of mental health become visible and knowable is through the various forms of calculation, mapping and calibration that the ‘psy’ professions have made possible. The psychological test was first designed to measure the intellectual abilities of school children and since then, psychological testing has entered into many spaces including the courtroom, the employment office and, as we shall see, the private homes of individuals. With the increasing salience of ‘psy’ practices and discourses, and the precise methodologies they have provided for constructing and calculating human difference, it could perhaps be said that part of neoliberal project involves the continual redrawing of the bounds of the knowable.

Self-administered mental health questionnaires differ from the psychological test administered in the courtroom or the employment office by virtue of being taken up freely and without the mediation of a psy expert or other authority figure. With the advent of the Internet, self-administered mental health questionnaires have proliferated. Some of the most common self-administered mental health questionnaires pertain to depression. In fact, when conducting an Internet search for the term ‘depression,’ the first related search term that appears is ‘depression test.’ This is not particularly surprising; depression is one of the most widely diagnosed mental disorders; it is also the leading cause of disability for Americans aged 15-44, according to the National Institutes of Health.

Commonly asked questions included in online questionnaires for depression ask whether the user has recently gained or lost weight, whether she has experienced indecisiveness, and whether she has been thinking about death. These may indeed be signs of depression, but the phrasing of these tests serve to consolidate the differences between the mundanities of human life (e.g. weight fluctuations) and the profundities of human life (e.g. reflections on mortality). This consolidation both reflects and energizes one of the primary features of neoliberal forms of government rationality. Specifically, the collapse of the mundane and the profound effectively renders all human life into the same calculable, scientific form that renders it actionable—something can be done with it.

Based on the user’s answers to the above questions, she will be placed into a category of ‘depression risk.’ Depression risk categories generally range from “high” to “low.” Notably there is not a “no risk” category and that is because no one is not at risk for depression, thus vigilance is always merited. These questions and categories render the previously ineffable ‘inner lives’ of individuals into outwardly measurable categories of personhood that serve as sites of intervention. The point of these categories, however, isn’t necessarily to erase any trace of uniqueness across individuals or to collapse subjectivity. These tests suggest that one ought monitor one’s unique symptom profile. Doing so will allow one to manage one’s mental state and to mitigate possible risks, ultimately allowing one to thrive and pursue the good life. And ‘thriving’ is not only good for the individual, it is also good for the state—healthy citizens are active citizens. Thus, the interests of the individual are aligned neatly with larger political and economic interests.

That these voluntary tests have become commonplace underscores a point that Graham Burchell (1996) has made about government rationality. Neoliberal forms of government don’t seek to squash or limit subjectivity; rather, they nurture and mobilize subjectivity, such that subjects can become “the object and target of government and the necessary (voluntary) partner or accomplice” (p. 23). These tests are taken up freely by individuals with an active interest in ‘discovering’ previously unknown or obscured information about their inner lives; this freshly discovered knowledge can serve as a rationale for various forms of self-intervention.

It is possible to say that self-administered questionnaires do not serve (only) the purpose of discovering previously unknown information about the self, they also aid in the production of particular forms of self-knowledge. These forms of self-knowledge suggest that a prudent form of action might be to adopt self-surveillance practices to monitor and mitigate risks to health status. For instance, if a user’s score places her in a “low risk” category, the test results page will often encourage her to repeat the test in two weeks, paying
particular attention to any physical symptoms or negative thoughts that occur in the intervening time. This practice of self-surveillance and pursuit of self-improvement indicate that one is alert to health risks, and is taking responsibility for the optimization of health status. Paying attention to, and mitigating depression risks becomes especially salient at a time when depression is a leading cause of work disability. When individuals freely take up these tests and place themselves on alert for these symptoms, they are “sharing the burden of governance” (LeBesco, 2011).

The wide availability and utilization of self-administered questionnaires for mental health risks underscores that which sociologists of health and medicine have been saying since at least the early 1990s: that health-talk has become “responsibility talk.” (Crawford, 2006). After all, without accountable, health-conscious subjects to voluntarily seek them out, these questionnaires would lack both an audience and a point. In utilizing these tests, the responsible health-subject is simply taking one of many steps down the path toward achieving what Greco (1993) calls her “duty to be well.” One crucial component of living up to one’s duty to be well appears to be taking up what might be called here the “duty to know”: the duty to actively, and without prompting, seek out information about individualized health hazards, and to rationally mobilize that information in the pursuit of health. In public discourse, enacting one’s “duty to know” is often packaged as “empowerment,” with the logic being that the more information one accesses, the more empowered one becomes. In order to live up to her linked duties ‘to know’ and ‘to be well’ the user of self-monitoring and self-surveillance, such as the weekly tracking of appetite or mood symptoms (as mentioned earlier). This tracking process entails that one remains in a heightened state of alert, paying special attention to her thoughts, behaviors and emotions in the intervening time.

Birth, death and ‘patient preferences’

As discussed earlier, the medical profession, and physicians in particular, were previously subject to criticism for what was considered excessive paternalism. This excessive paternalism is sometimes said to have stemmed medicine’s autonomy—it had fewer consumer “checks” in place that could hold it accountable for unsatisfactory performance. This paternalism also meant that patients had limited opportunities to exercise agency in the context of physician-patient interaction. Now, the medical profession has professed a newfound interest in and respect for ‘patient agency’ and seeks to nurture patient agency in various ways. For instance, Soren Holm (1993) suggested that, “If patients are to be involved as equal (and maybe even senior) partners in decisions concerning their health care, then doctors will have to adjust their role from being the sole decision-makers to being the expert advisors” (p. 109). And indeed, patients are encouraged to play a more active role in their healthcare, to make decisions and to exercise authority.

While “restoring agency” to patients sounds vague as an objective, there are concrete practices that indicate the ways in which patients are enjoined to become more involved in their own care. Two of the most important medicalized events in a person’s life—birthing and dying—are two events over which the patient is often expected to exercise greater authority. Both of these medical events have given rise to institutional forms that ask patients to specify which technological interventions they would like to receive, or decline, in the event of labor or end-of-life care, respectively. In the case of end-of-life care, this institutional form is sometimes called the “Patient Preferences Worksheet.” This worksheet asks patients whether they would like to receive life-sustaining interventions such as antibiotics, transfusions, defibrillation, tube feedings, chest compression and so on. The Patient Preferences Worksheet challenges, or complicates, the notion of expert authority in medicine. As Lisa Keranen (2007) explains, “Patients, prodded by the autonomy movement, and administrators, activated by the bottom line, called physicians’ previously unassailable authority into question” (p. 324). While few would argue against the prospect of giving patients more agency in the context of decisions as intimate and irrevocable as end-of-life care, some are wary of the motivations for, and consequences of, the worksheet. Keranen states that while the worksheet “is deployed in the name of promoting patient autonomy and encouraging sound decision making, the Worksheet frames decisions as matters of technological as opposed to moral agency, and cultivates a radical restructuring of deathbed subjectivity” (p. 372). A sole focus on the technical means of death eclipses possible consideration of the ethical ends of life.

The patient-authored birth plan fulfills many functions that are similar to those that Keranen describes above. The birth plan indicates which medical treatments the expectant mother prefers to receive, or decline, during the course of her labor. These choices include treatments such as fetal monitoring, pain relief, epidural, episiotomy, etc. The purpose of these choices is to allow expectant mothers to determine the shape that she wants her labor to take. The problem is, the birth plan is often subject to change. Monica Crossley, (2007) reflecting on her own labor, questions whether
In order for me to have made a genuine choice in this process, a number of conditions would need to be fulfilled...First, I would need to have had genuine desires and preferences. Second, I would need to have had an understanding of the situation I was in and the options open to me. Finally, I would need to have had some means or technique of weighing up the potential outcomes and arriving at a decision.

The mere existence and distribution of the form does not ensure that any of the following criteria will be met. While the objective of these forms is, in part, to liberate patients from the previous paternalistic practices of physicians, sometimes the inducement toward choice can have the opposite effect of liberation. Crossley explains that after being admitted to the hospital and having her labor induced (contrary to what was previously specified on her birth plan) she felt liberated when she was relieved of her duty to make all the decisions regarding her own medical care. She states, "I felt a sense of relief flood over me—al last, someone was taking things out of my hands and I could allow myself to ‘let things go’ if only because that’s what the medical staff were telling me I had to do." (p. 553). Though she experienced relief when induced, Crossley’s feelings later turned into disappointment in herself. It seemed as though she had failed to live up to the type of birth that she herself had ‘decided’ upon.

In short, these forms represent one of the defining characteristics of neoliberalism. Death and labor are two processes that are deeply fraught with ethical, social and political implications. And yet, the preferences worksheets and birth plans recast these problems as “nonpolitical and non ideological problems in need of technical solutions” (Ong, 2006, p. 3). These worksheets frame “choice” within labor and end-of-life care solely as matters of technological intervention, pushing out the possibility for other kinds of discourse. Furthermore, by so intensely implicating patients in the course and outcomes of their own care, the burden of responsibility (including legal responsibility) that comes with expertise is placed instead on the shoulders of patients. The consequences of this unprecedented patient autonomy have seeped into the economic realm where, as Crawford explains, employers have “seized on this favorable climate” (wherein patients are expected to be more actively involved in their own care) by shifting more and more of the costs of healthcare over to employees.

Conclusion
Neoliberalism is not only a philosophy of governance aimed at achieving particular forms of economic and political order, it is also a way of thinking and a way of talking. David Harvey (2006) says that, “Neoliberalism has, in short, become hegemonic as a mode of discourse. It has pervasive effects on ways of thought to the point where it has become incorporated into the common-sense ways that many of us interpret, live in, and understand the world” (p. 3). This essay has given consideration to some of these common-sense ways of living, as health-subjects, within a society that has been saturated by neoliberal thinking. Part of the hegemonic power of neoliberal discourse derives from the fact that it effectively provides social and political questions with technical and ostensibly nonideological answers. Because health, as a value and a goal, already appears to be largely neutral or value-free, health discourses and practices are tools of special import for neoliberal forms of governance.

The three health-practices explored above all strongly implicate the role of the patient in the management of her own care, and all work to cultivate health subjectivities that are amenable to neoliberal forms of governance and neoliberal values. In the case of direct-to-consumer genetic tests, the patient (or ‘consumer’) actively, voluntarily and ‘responsibly’ takes part in the projects of risk-calculation and risk-mitigation—projects that are a fixation of contemporary Western society. These tests conjure a sense of dual responsibility: the consumer is responsible both to herself to know all that can be known about her individual, bounded and autonomous body so as to mitigate health risks; she is also responsible to translate this knowledge into actions that will possibly impact others. In the case of the self-diagnosis questionnaires for depression, the voluntary test-taker “shares the burden of governance” by self-monitoring and managing possible mental health ‘symptoms’ through the ongoing tracking of moods. This helps to ensure that her mental-health status remains strong and active, given that depression is a leading cause of works disability. In the instance of patient-centered decision making in labor and end-of-life care, the patient is enjoined to become an active participant, sometimes even a “senior partner” in the management of her own health care. This helps to create an atmosphere in which patients are increasingly accountable for the management and outcomes of their care, which in turn lessens the legal burdens of responsibility carried by hospital administrators and physicians. This atmosphere of heightened patient accountability can be leveraged by employers, who have a rationale for foisting a greater proportion of insurance costs onto their employees. Overall these three practices
demonstrate how 'health', as a seemingly nonideological value, can be instrumentalized to nurture certain kinds of health subjectivities that render individuals active, alert and accountable. These health subjectivities, in turn, map smoothly onto the goals and values that characterize neoliberal policies and philosophies.

References