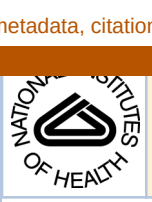

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Personalized Genomic Medicine and the Rhetoric of Empowerment

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Abstract

Advocates of "personalized" genomic medicine maintain that it is revolutionary not just in what it can reveal to us, but in how it will enable us to take control of our health. But we should not assume that patient empowerment always yields positive outcomes. To assess the social impact of personalized medicine, we must anticipate how the virtue might go awry in practice.

Human genome research owes a debt of gratitude to the historian of science Thomas Kuhn, who introduced the idea that conceptual change in science can happen through "paradigm shifts" that go beyond incremental problem-solving.[1] While Kuhn was agnostic about whether such revolutions necessarily constitute "progress," the popular understanding has become that paradigm shifts are the most effective form of scientific progress. As a result, appealing to the prospect of a "paradigm shift" for biomedical science has been successful in generating public and private investment in genomics research, and a wide variety of stakeholders promote its translational goals as a new paradigm for medicine, under the banner of "personalized genomic medicine."[2] As Francis Collins, long-time leader of human genomics research in the United States, puts it:

> We are on the leading edge of a true revolution in medicine, one that promises to transform the traditional "one size fits all" approach into a much more powerful strategy that considers each individual as unique and as having special characteristics that should guide an approach to staying healthy. … If you are interested in living life to the fullest, it is time to harness your double helix for health and learn what this paradigm shift is all about.[3]

A decade after the completion of the Human Genome Project, the widespread appeal of personalized genomic medicine's vision and potential virtues for health care remains compelling. Advocates argue that our current medical regime "is in crisis as it is expensive, reactive, inefficient, and focused largely on one size fits all treatments for events of late stage disease."[4] What is revolutionary about this kind of medicine, its advocates maintain, is that it promises to resolve that crisis by simultaneously increasing the ability to be "personalized," "predictive," "preventive," and "participatory." Some call personalized genomic medicine "P4 Medicine," inscribing these cardinal virtues into the movement's name.[5]

All of these putative virtues have interesting implications for the future of health care. In this essay, we are especially interested in the claims that personalized medicine will lead to a more "participatory" or "patientcentered" approach to health care, in which patients are "empowered" to take more personal control over their care. The rhetoric of patient empowerment is nothing new in health care, but personalized medicine is an interesting case study because it portrays empowerment as one of its key virtues and as a mechanism for fixing the health care "crisis."

Who Emphasizes "Patient Empowerment"

Personalized genomic medicine is the product of many minds and has many interpretations. A close reading of the literature yields at least three concentrations of stakeholders who are heavily invested in empowerment rhetoric:[6] (1) direct-to-consumer genomic scanning companies and the "early adopters" of their services; (2) the leaders of genomic medicine programs at premier biomedical research and health care institutions; and (3) genomic medicine's government sponsors and advocacy groups.

Direct-to-consumer companies and early adopters

It is no surprise that the theme of patient empowerment is invoked in the marketing of companies that sell genetic testing and genome scanning directly to consumers and in the enthusiastic writings of their customers. Capitalizing on the "open-source" ethos of the Internet, these companies solicit business online with marketing rhetoric that echoes the postmodern suspicion of authority and paternalistic expertise. As the company 23 and Me explains, "We believe that your genetic information should be controlled by you."[7] In this context, claims that, for example, "getting to know your personal genome will empower you and provide you with a road map to improve your health" are ubiquitous.[8] This appeal also clearly resonates with the early adopters—those who use and blog about these services—whose reported reasons mirror the empowerment rhetoric of the companies' marketing materials.[9]

Appeals to increased personal control are not unusual in a marketplace environment. We expect companies to exaggerate claims as they market their products. What is interesting is that the claims made by the "consumer genomics" industry and their customers do not stray far from mainstream biomedical rhetoric about personalized genomic medicine. The public might not expect academic institutions—especially those that operate on public financial support—to engage in the same kind of marketing strategies as private industry.

Premier research and health care institutions

Translational genomic research programs such as the Institute for Systems Biology and the Coriell Institute for Medical Research often espouse patient empowerment as one of the goals of their research.[10] At the P4 Medicine Institute, the "passive patient will be transformed into the engaged consumer who takes ownership of his or her own health. Healthcare will become enjoyable, actionable, and effective"—or so its Facebook page claims.[11] Prominent hospital-based programs like the Duke Center for Personalized Medicine and the Center for Personalized Healthcare at the Cleveland Clinic also stress that their mission is to "empower patients to understand their unique health needs and access resources that will help them achieve optimal health,"[12] or to "empower patients to actively participate in their healthcare."[13]

This is not traditional rhetoric for premier medical institutions, which have a financial interest in reinforcing their special expertise and have in the past favored more paternalistic, care-centered marketing.[14] It is, however, consistent with a contemporary refrain about social policy in the United States, including health insurance, which emphasizes personal responsibility and self-reliance over reliance on the government or other services.[15]

Government sponsors and advocacy groups

Personalized genomic medicine's empowering potential has also been embraced in federal policy. Empowerment rhetoric appears in its promotion as the primary "translational" goal of the genomic research sponsored by the National Institutes of Health,[16] and former Health and Human Services Secretary Michael O. Leavitt made the *Personalized Health Care*

Initiative a priority initiative of the Department of Health and Human Services.[17] Supporting these efforts is the leading advocacy group for the advancement of personalized medicine—the Personalized Medicine Coalition, which promotes personalized medicine as "proactive and participatory, engaging patients in lifestyle choices and active health maintenance to compensate for genetic susceptibilities."[18]

In sum, although their other interests vary, actors across influential stakeholder groups in personalized medicine concur that patient empowerment is a primary virtue of the "paradigm shift" they espouse. As one review concludes:

> The main characteristic of the evolving health care delivery model is that it is starting to become more collaborative; moving to a co-diagnosis, co-care model between physicians, patients and other parties. The physician could start to be seen as a colleague and advisor, as one of many input sources in fashioning a care plan. The patient could become more of an informed participant, an active responsibility-taker, the owner, administrator, and coordinator of his or her health program and health data.[19]

Whatever rationales link this virtue to the genomic technologies underpinning personalized medicine, this widespread support may raise the profile of efforts to empower patients as the personalized approach to medicine is implemented. Efforts to empower patients must be attempted with care, however, because social scientific research has already shown that patient empowerment practices have a double-edged quality that sometimes cuts against society's health care interests.

Empowerment as a Double-Edged Virtue

Supporting the patient's voice in clinical encounters has been the hallmark of medical ethics and the "patients' rights" movement in health care law since the 1970s.[20] Within genomic research, discussions of the active, empowered patient have often centered on early adopters of technology as "lay experts" in a "genetic citizenry" who may actually help construct and advance the technology.[21] But studies of that movement show that the virtue of patient empowerment has a correlative vice—the relocation of responsibility for health care away from social and political realms and onto the shoulders of patients. This shift has long been signaled in the writings of medical sociologists and bioethicists, who have warned that "the emphasis on individual empowerment often disguises the fact that personal genomics is pushing the individualization of responsibility for health one step further."[22]

The shift should prompt concern within the personalized genomic medicine movement because it may increase pressure on patients to comply with physicians' recommendations. Even more worrisome is that individuals who are unable to become "health-creating persons" or who do not make the "right" health choices are easily "marked out as irresponsible and hence unfit to be self-governing citizens."[23] These problems become increasingly complicated when the supposed source of the condition is understood to be genetic.

We should not assume that patient empowerment always yields positive outcomes. To assess the social impact of personalized medicine, we must anticipate how this virtue might go awry in practice. To prevent health care responsibilities from shifting in counterproductive ways for both clinicians and patients, those promoting personalized medicine must be clear about what goals their appeals to empowerment are meant to achieve, and consumers must weigh the relative value of these goals against their own interests. As a starting point, the promoters could provide evidence of the extent to which genetic information brings

actionable intelligence for patients. If the information given to patients has no effect on their actions, then the promise of patient empowerment is empty.

The Contingency of Empowerment

Most of the virtues ascribed to personalized genomic medicine flow from the fact that genomic tools focus attention on the role of genetic factors in health and disease. Genomic medicine is "personalized" because it aims to tailor health care interventions to the individual patient's unique constellation of genetic factors. It is "predictive" because it uses genome-wide genetic associations to assess future health risks, and it is "preventive" if those genomic risk assessments can lead to prophylactic interventions that allow predicted problems to be avoided or forestalled.

But how does the link between genomic medicine and patient empowerment come about? It is difficult to see how patient empowerment necessarily and simply flows from genomic science and technology. Genomic science can provide two kinds of information relevant to health care decisions: (1) pharmacogenomic information about a patient's chances of responding well or poorly to a therapeutic regimen, and (2) genomic susceptibility information about a patient's chances of resisting or succumbing to other environmental or degenerative health threats. Neither kind of information obviously has a role in empowering patients that is analogous to its role in understanding, preventing, or treating disease.

Pharmacogenomic information

A patient and a physician might use pharmacogenomic information to make more informed choices about alternative treatment regimens, but there is nothing about this information that inherently shifts the nature of the patient's relationship with the physician or increases the patient's ability to control the choice between treatments. Pharmacogenomics decision-making still takes place within the traditional fiduciary paradigm in which patients either reject or, more likely, accept professional recommendations.

In fact, because genomic medicine generates more risk information and makes that information the key lens for approaching health and disease, patients may actually find that they have *less* ability to influence health care decisions and treatments. When the relative risks and benefits of treatment choices are uncertain, patients' preferences about how to gamble are given significant weight. If molecular profiling can help clarify treatment tradeoffs, however, physicians will be able to give their patients "doctor's orders" more confidently and with more authority.

Many programs seem to acknowledge this by framing the "personalization" of genomic medicine as "allowing healthcare professionals to customize your treatment for what works best for you" so that "your physician can treat you with greater precision, fewer side effects and with better results."[24] According to the American Medical Association, "genetic testing, except under the most limited circumstances, should be carried out under the personal supervision of a qualified health care professional" because "without the guidance of a physician, genetic counselor, or other genetics specialist, test results could be misinterpreted, risks miscalculated, and incorrect health and lifestyle changes pursued."[25] Pharmacogenomic information is blind to psychosocial or cultural considerations that might result in different definitions of "responding well" and "responding poorly" for patients and their physicians, and there is little research on the possible influence of cultural factors on pharmacotherapeutic responses.[26]

Genomic susceptibility testing

In contrast, genomic susceptibility testing carries greater potential to disrupt the traditional therapeutic relationship between patients and physicians. Because its predicted health risks and prospects for prevention are largely matters of diet, lifestyle, and occupational and environmental exposure, genomic medicine takes some of the decision-making out of the hands of physicians and puts it into both the hands of patients and of the social institutions that regulate these other dimensions of life. To the extent that those institutions are less paternalistic than traditional medicine, this shared responsibility should expand the ability of patients to affect their health decisions. It is, therefore, not surprising that the attention of medical stakeholders is drawn to pharmacogenomics, while the attention of users and providers of "consumer genomics" is instead drawn to genomic susceptibility testing.

Ironically, however, the risk information provided by genomic susceptibility testing rarely, if ever, remains at the individual level. Instead, it is usually mapped onto group-level experiences and measurements. The first page of a report by the 2008 President's Council of Advisors on Science and Technology makes this point clear:

> "Personalized medicine" refers to the tailoring of medical treatment to the individual characteristics of each patient. It does not literally mean the creation of drugs or medical devices that are unique to a patient, but rather the ability to classify individuals into subpopulations that differ in their susceptibility to a particular disease or their response to a specific treatment. Preventive or therapeutic interventions can then be concentrated on those who will benefit, sparing expense and side effects for those who will not.[27]

Because of its statistical foundation, genomic information can only illuminate the health risks of genetic superfamilies, and the best genomic medicine can do is classify individuals as members of those families. It will be a long time before individualized treatment is a routine part of disease management. As a result, some argue that what is often referred to as "personalized medicine" should more accurately be described as "stratified medicine."[28]

Of course, it would be a major rhetorical retreat for genomic medicine to give up the idea of individualized assessments and "tailored" treatments in favor of stratifying patients into categories that are, ironically, not so far from a one-size-fits-all approach in the end. Most promoters of genomic medicine therefore express hope that the present state is a stop-gap stage. As Francis Collins writes:

> The goal for personalized medicine must be to move as swiftly as possible toward the identification of individual risk factors, be they environmental or genetic, that play a direct role in disease risk. Racial profiling in medicine, even if well intentioned right now, should recede into the past as a murky, inaccurate, and potentially prejudicial surrogate for the real thing.[29]

This hope for greater personalization has to be an article of faith for promoters of genomic medicine, in part because the general prospects of individual and community empowerment in the United States are so intimately affected by population stratification. As Collins suggests, against the backdrop of social and political stratification, population classification schemes based on racial and ethnic categories can be actively *disempowering* for individuals, by encouraging potentially prejudicial associations between their group affiliations and health care risks.

Why Emphasize Patient Empowerment?

Patient empowerment is not a particularly revolutionary idea, nor is it unalloyed as a virtue, given the responsibilities it invokes. It has no clear source in genomic tools, and, indeed,

these tools may even undermine patient empowerment in the context of traditional clinical relationships between physicians and patients. Outside the clinical setting, too, the potential sources of patient empowerment would seem to collapse into the ambiguous benefit of being simply classified into a social group with known health risks. Why, then, is patient empowerment emphasized by personalized genomic medicine's proponents as a cardinal virtue of the paradigm? The literature suggests at least three possible rationales: (1) that patient empowerment makes a virtue of clinical necessity because much of the preventive promise of genomic medicine depends on individual patient lifestyle and behavior modification; (2) that it imports a free-standing moral concern against medical paternalism, fueled by the marketing interests of the "consumer genomics" industry; and (3) that it exploits the appeal of enhanced patient autonomy in order to generate political and public support for the paradigm. The literature provides enough illustrations of each to make them all merit further study.

A virtue of necessity?

In her study of personalized genomic medicine, Alison Harvey quotes an early user's telling testimonial about its empowering capacity:

> Since being given the results of my test, my initial feelings of fear and depression have gradually been replaced by a sense of empowerment. … "There is no need to worry, providing you change your life-style," [the doctor] kept repeating. So that is what I have decided to do. I now have the greatest possible incentive to change my way of life.[30]

On the one hand, it is positive that this patient came away with a sense of empowerment and managed to overcome his initial fear and depression. On the other hand, the doctor's repeated emphasis on general lifestyle change may have been offered only in the absence of more meaningful or specific advice. But by styling participation as an expansion of patient control, the concept of empowerment allows for the creation of complementary obligations on the patient's part. As patients make more "responsible" choices, they will also have and perceive positive results, which further reinforce those choices. Of course, this also increases the risk that personalized genomic medicine might go awry in ways that other responsibility-inducing empowerment efforts have in the past, which should put us on alert for any unintended consequences of empowerment.

A moral stand against paternalism?

A second possible source of personalized genomic medicine's commitment to patient empowerment is a moral rejection of medical paternalism. This rejection taps a longstanding social conversation about the need for shared decision-making in medicine, fueled by a growing concern over medical error and the demise of the traditional sick role. As skepticism about physicians' abilities to interpret genomic information grows, so does public interest in gaining access to that information directly. As one personalized medicine advocate writes:

> Designating physicians as gatekeepers for genetic information isn't just disempowering—it's basically sticking healthcare in a time capsule for a decade or more, until physicians get up to speed. … This persistent paternalistic streak also reflects a lack of faith in the ever-more empowered patient, who is eagerly scouring the Internet for the latest research concerning her condition.[31]

Once again, of course, this rationale will be most attractive to stakeholders *outside* the traditional clinical setting, such as the direct-to-consumer genetic testing companies and the consumers who use their services. One common justification for marketing genomic services to consumers is the hope that a "greater sense of individual ownership of personal

genomic information could replace overly complex and paternalistic institutional proxies for the protection of personal genotype and sequence data, and also could encourage research participants and patients to become better educated regarding genetic contributors to disease."[32] For health policy purposes, the implication of this argument is that the resulting education and ownership might, in turn, lead to better health outcomes. This conjecture, however, actually stands in direct contrast to much empirical research, which shows that genomic information has no real impact on patients' perceptions of control, information seeking, or health behaviors.[33]

A way to create demand?

Every revolution needs the people's support to succeed, and for personalized genomic medicine, this means the allegiance of patients and health care consumers. One way this need gets acknowledged by some proponents is through their concern to insure that the public's first impressions of personalized medicine are not negative. As one critic of commercialized genomic medicine argues, "The unregulated and unvalidated introduction of genomic self-testing may undermine physicians' efforts to secure public confidence and acceptance of this vital component in the emerging field of 'personalized' medicine."[34] But the public's role in the personalized medicine revolution has the potential to go much further than passive acceptance. For many, the value of empowering patients is that it gives them a stake in the movement itself, and it enlists them in helping the revolution succeed at both clinical and public policy levels.

At the clinical level, the cause is advanced by patients who challenge their physicians to adopt the tools and services of personalized genomic medicine. As one promotional manifesto puts it:

> Seventy million Baby Boomers, now or soon-to-be over age 60, seek to live not just longer, but healthier and more productive lives. When they fully understand and embrace personalized medicine, it will create an unprecedented level of consumer demand. When physicians feel they may incur liability for not offering a test that provides information on optimal care, the impetus toward adoption will be even greater.[35]

At a policy level, personalized medicine's proponents also need public help to ensure that the health care system is structured to accommodate the approaches and needs of its practice. Advocacy organizations like the Personalized Medicine Coalition and the National Health Council use empowerment language to encourage public involvement on behalf of legislation designed to facilitate personalized genomic medicine, like the Genomics and Personalized Medicine Act (HR 5440).[36] As one consumer advocate argues, "it is our responsibility as patients to ensure the power of [personalized genomic medicine] is leveraged for us each time we interact with the healthcare system."[37] Moreover, for the parts of the health care system already committed to personalized medicine, a galvanized patient population can also help to promote health care reimbursement and policies that advance the movement's interests.

The appeals to "patient empowerment" in the promotional literature for personalized medicine show the importance of tracking emerging discourse about this "paradigm shift" if we are to fully anticipate its social implications.[38] We can see several forks in the road ahead. First, since the virtue of patient empowerment ultimately has a weak grip on personalized medicine's pharmacogenomics side, it could easily be jettisoned when decision-making falls into medicine's traditional domains of authority, subverted as a device for increasing patient compliance with medical recommendations, or simply exploited as a campaign promise that serves only to garner public support and generate demand. For those invested in employing patient empowerment as a facet of personalized medicine to serve as

a moral stand against medical paternalism, anticipating and avoiding these outcomes will be important.

The health benefits of much of personalized medicine's genetic risk profiling side will indeed depend on patient decision-making, but this fact turns out to have potentially worrying implications of its own. For this side of the field, emphasizing patient empowerment might unfairly inflate patient's responsibilities for their health, either by tying their empowered role to obligations to make decisions that conform to social expectations and interests, by enlisting patients in quasi-contractual ways to help secure the success of the personalized medicine paradigm through their decision-making, or by abandoning other environmental, structural, and regulatory approaches to health promotion and risk reduction in order to force the "choices" that individuals must make for themselves. The idea of patient empowerment may run up against not only the limits of patients' control over their health, but also the limits of patient control over health care systems. For those committed to preserving a more generous vision of health care as a social good, these dynamics are important to anticipate and avoid as the practice of personalized genomic medicine moves forward.

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