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Personalized medicine or public health? Bioethics, human rights, and choice



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ABSTRACT

The major medical/scientific research project of the past two decades is the human genome project and its suggested clinical applications. The project can usefully be framed as a quest to cure disease, especially cancer, and even to defy mortality. The hero of this quest is the project leader, who currently is trying, almost desperately, to “translate” the science of the genome into public health practice (screening) and the practice of medicine, often termed tailored, precision or “personalized medicine.” In America’s dysfunctional and patchwork healthcare system, adding another layer of extremely expensive and (to date) marginally effective screening procedures and genetics-based cancer treatments is a hard sell. Nonetheless, framing the human genome project as a quest for added life can make it seem altogether normal, even natural, and can help rally the public to its support. A second, parallel quest is the public health-political quest for a system that guarantees universal access to healthcare for Americans. The ultimate success of this quest will depend not on any scientific or medical breakthrough, even a genetic one, but on political will. Creating and sustaining political support for universal healthcare access will require, I suggest, the deployment of stories of real Americans whose lives have been made much more miserable by the lack of access to decent healthcare. These two quests are converging in ways that may make them incompatible because of the extreme expense of personalized medicine, and, at least so far, its inability to add more than marginal benefit to the lives of most Americans. Nonetheless, until Americans are more comfortable accepting death, we will continue to fight our mortality with activities we frame as quests, making our dysfunctional healthcare system less and less able to respond to the health needs of the American public.

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Medicina personalizada ou saúde pública? Bioética, direitos humanos e escolha

R E S U M O

O Projecto do Genoma Humano (PGH) (*Human Genome Project*), bem como as suas possíveis aplicações clínicas, constituem o maior projecto de investigação biomédica das últimas duas

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décadas. Este Projecto pode ser descrito como uma jornada em busca da cura para a doença (em termos gerais), para o cancro (em particular) e, em última análise, uma tentativa de desafiar a nossa própria mortalidade. O herói desta jornada é o líder do Projecto, que, actualmente tenta, quase desesperadamente, “traduzir” a ciência do genoma para a prática em saúde pública e em medicina, um esforço que é denominado global e genericamente como medicina personalizada. No contexto de um sistema de saúde disfuncional e incompleto como o Americano, é difícil persuadir os cidadãos que é útil adoptarem-se tratamentos e rastreios para o cancro baseados na genética, uma vez que estes são extremamente dispendiosos e apenas (pelo menos à data), marginalmente eficazes. Todavia, enquadrar o PGH como uma jornada em busca de mais tempo de vida pode conferir ao mesmo um cariz de normalidade (quase de naturalidade) que poderá ajudar a mobilizar o público em seu redor. Uma segunda e paralela jornada, esta simultaneamente política e de saúde pública, caracteriza-se pela procura de um sistema de saúde que garanta a todos os Americanos o acesso universal a cuidados de saúde. Ora, o sucesso último desta procura dependerá não de uma descoberta científica ou biomédica, mesmo que esta provenha da área da genética, mas da existência de vontade política. Mais, criar e manter apoio político para o acesso universal à saúde requererá, sugiro, o recurso às histórias de vida dos Americanos reais, que se tornaram tão mais miseráveis pela falta de acesso a cuidados de saúde decentes. Estas duas jornadas têm convergido de tal forma que, devido aos custos enormes da medicina personalizada e, pelo menos até hoje, da sua incapacidade de conferir mais do que benefícios marginais à vida da maioria dos Americanos, elas se tornam hoje quase incompatíveis. No entanto, até que a América se torne mais confortável perante a aceitação da morte, continuaremos a combater a nossa mortalidade com actividades que melhor se caracterizam como jornadas, ajudando a que o nosso sistema de saúde, já de si disfuncional, se torne cada vez menos capaz de responder às necessidades de saúde dos Americanos.

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“The new and rapidly evolving field of genomics offers considerable possibilities for the improvement of human health. . . but the full extent of its possible hazards are not yet fully appreciated.”

World Health Organization, *Genomics and World Health*, 2002.

Modern medical research and mass marketing conspire to enable Americans to deny death by suggesting that researchers may yet discover a medical “fountain of youth.” Even if the fountain cannot enable immortality, the suggestion is that it will at least be able to postpone death for a very long time. Medical progress itself is now measured almost exclusively by longevity—in terms of both overall life expectancy, but also in terms of survival rates following treatment for disease. Quantity of life continues to be relentlessly pursued and privileged over quality of life. The focus on increasing longevity in medical research is enabled, and even encouraged, by the arts—including classic story telling methods, including the use of the quest myth, and the creative use of metaphor.¹

In this chapter I examine the application of the quest myth and related metaphors to the most celebrated medical research project of the past two decades, the human genome

project, and the ongoing attempt to “translate” genomics into clinical medicine, commonly termed “personalized medicine,” and/or public health. These two goals may, however, be incompatible. As James Evans and his colleagues put it in early 2013, “Genomics and public health have been uneasy bedfellows for some time.”¹

Genomic “personalized” medicine

Personalized medicine, medicine tailor-made for each individual patient, has as its premise the belief that an individual’s unique genome determines (at least probabilistically) the way the individual will respond to specific drugs, diets, exercise regimes, and other treatment or risk reduction strategies. The goal is often stated as replacing “one size fits all” medicine with “the right drug, for the right patient, at the right time.” This is a great oversimplification. What is really at stake is stratified medicine—treating people with similar genetic profiles the same. The most prominent metaphor is to use the individual’s DNA, the “blueprint of life,” to “tailor” treatment regimes that are most likely to lead to successful treatment—measured in increased length of life, sometimes simply termed “saving lives.”²

The dream of personalized medicine is largely powered by the successes of the personal computer and the smartphone. Can technology do the same for genome testing by driving down the price and improving the accuracy and speed? By early 2013 the answer is maybe. As explained by an infor-

¹ Portions of this chapter are adapted from and continue the exploration begun in Annas, GJ. Bioethics and genomics. In: Andrew Clapham and Mary Robinson, editors. *Realizing the right to health*, Ruffer & Rub, 2009, and Annas GJ. *The songs of spring: quest myths, metaphors, and medical progress*. In: Paul MacNeil, *The arts and ethics*, Springer, 2013.

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