

## Ref.

## Medicine Without Limits

Daniel P. Sulmasy

Even before Mary Shelley wrote *Frankenstein*, everyone knew that medicine had innate tendencies to exceed reasonable boundaries in the exercise of its powers. Those powers have grown considerably since the early nineteenth century, and Andrew Stark recognizes that society now desperately needs to figure out a way to tame medicine by limiting its scope.

For the last decade or more, the standard philosophical approach

to this problem has been to try to draw a distinction between curing diseases and enhancing human traits. But this

approach, says Stark in *The Limits of Medicine*, raises two problems. First, some groups (paradigmatically, a subset of the deaf community) consider themselves not diseased but merely different. Arguing that they have developed a distinct language and culture, curing deafness would, in their view, result in "cultural genocide." The second problem is that since no one has been able to define disease in a universally acceptable way, Stark, like many observers, concludes that the very definition of disease is ultimately subjective. If this is true, then there is no objective basis for distinguishing between legitimate therapy and illegitimate enhancement, or between medical care and "cultural genocide." What if "black skin" comes to be thought of as a "disease" to be overcome? If diseases are defined subjectively, someone might offer to "cure" this "disease," and there would be no principled way to say this is wrong. As currently construed, Stark concludes, the therapy/enhancement distinc-

*The Limits of Medicine* by Andrew Stark Cambridge ~ 2006 ~ 264 pp. \$25.99 (paper) tion will not suffice to save medicine from its megalomaniacal tendencies, because it offers no clear grounds for taming

medicine by limiting its province to the cure of disease.

To demonstrate the inadequacy of the therapy/enhancement distinction, Stark considers the two "frames" people use to defend it. If one tries to define disease in terms of the *population* at large, Stark suggests that the project fails, at least in part, because human norms continue to change. For example, "short stature" and "long life" now mean something different than they did in the Middle Ages. Disease cannot be defined by reference to population norms. If one

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turns to the *individual* to try to determine a cut-point between therapy and enhancement, the project falls prey to the possibility that any individual could consider himself diseased by any subjective standard. So, for instance, one might subjectively consider an unshapely nose a "disease" for which one might legitimately request corrective "therapy." There would be no stopping medicine; no limits could be drawn. Moreover, Stark notes that those who have attempted to draw a distinction between cure and "cultural genocide" have met frequent resistance: militants in various disease groups simply reject all talk of cure as an attack on the "differently abled."

C tark's proposed solution to our Oconundrum is a "shift in frame." Instead of examining the therapy vs. enhancement question from the perspective of society or of the individual, he proposes adopting the perspective of those affected by the condition in question. He avers that if those affected by a condition legitimately believe that a medical intervention is necessary to make an individual whole, then the intervention is a cure, not an enhancement. Stark then stipulates several rules for determining whether a claim for a therapeutic intervention is indeed "legitimate." First, if the phenotypical features associated with the condition are distributed normally across the population, then no phenotype can be considered either normal or abnormal.

Second, if the phenotypical features associated with the condition are distributed in a skewed fashion across the population as whole, then anyone clustered around the modal portion of the curve (i.e., the "hump") is free to consider his or her condition normal or abnormal, while those at the "tail" of the distribution must consider themselves abnormal. Third, if an individual desires a medical intervention to change himself or herself to any phenotype anywhere along the spectrum, the medical intervention will be legitimate so long as at least one person has been able to achieve that desirable phenotype without the use of medical interventions. Fourth, if there are two ways of considering the distribution of the phenotypical feature across a population (what he dubs a "conflict of curve"), then "the one that is less encumbered by biological notions of normality is preferable" for making these determinations of legitimacy.

This is step one, and if it all sounds a bit confusing (and confused), it is.

Step two is to determine whether the intervention would result in cultural genocide, not from the perspective of those affected by the condition but from the perspective of society as a whole. Would cure of the condition, eliminating it from the face of the earth, result in the destruction of a valuable culture? Or could that culture survive in society as a whole through the heritage it passes on to the rest of society? If the culture

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can persist beyond the disappearance of the disease, then eliminating the disease is not "cultural genocide" but a legitimate medical cure and thus a legitimate pursuit for medicine.

Stark calls his philosophical method "Rawlsian reflective equilibrium." He examines eight different medical conditions by running them through the elaborate set of tests described above to see whether the results square with our intuitions about what should count as legitimate medicine and what should be beyond the "true" limits of medicine. And guess what? With only a slight bit more prestidigitation, it turns out that this Rube Goldberg machine actually produces the result that he was after-medicine can do anything that anyone wants, unless it offends the secular liberal academy's holy trinity of race, gender, and sexual orientation. Thus, pregnancy is a disease that can be "legitimately cured" by abortion, while homosexuality is normal because, across the population as a whole and prescinding from silly notions like the biological differences between men and women, it turns out that as many people are attracted primarily to male human beings as are attracted to female human beings. So, attraction to one sex or the other sex by any sex is normal. Yet, of course, while shades of skin color may likewise be distributed normally across the population, if an African-American wants to take a "Michael Jackson pill" and

become white, he would be engaging in cultural genocide and it would be wrong for medicine to help him.

Tissing in all these assertions Lis the slightest shred of justification for any of these rules. I am no Rawlsian, but give Rawls his due—this is not what he meant by "reflective equilibrium." Rawls would demand publicly accountable justifying reasons for the public policy positions one takes. I kept reading Stark's book over and over, looking for the reasons he might have to justify any of these complicated "tests" and "rules." I never found any justification for any of them except that they somehow eventuate in his own intuitions (which he presumably shares with his colleagues and friends). He sometimes appears to give a justification, but on closer examination it turns out to be a mere assertion. Why, for instance, when there is a "conflict of curve" should one pick the curve "less encumbered by biology"? Stark's answer is that to do otherwise is to beg the question in favor of biology. But it seems to escape him that to do the opposite is to beg the question against biology. And why should deciding which curve "wins" the "conflict of curve" settle anything philosophically anyway? In the end, what can be arbitrarily asserted can be arbitrarily denied, and thus even what appears to be a justifying argument hardly amounts to one.

Stark's anti-biological musing is amusing. Consider the following pas-

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sage: "To make some prior assumption about a person's biological functioning ... and on that basis to construct the curve on which a medical condition is to be determined, is to get ourselves into a position where some phenotypes might be normal for one person and abnormal for another based on their genotypes." Stark thinks this is obviously blatant discrimination. Once more, however, what passes for a justification is no justification at all. Counter-examples are easy to imagine. Physicians think it is abnormal for an adult Caucasian male to be four feet six inches tall, but they consider the same phenotype in an adult male of the Mbuti tribe of the Congo to be normal, merely because they have different genes. Physicians think that a hemoglobin of 12 is abnormal in an adult with an X and a Y chromosome (i.e., a man), but normal in someone with two X chromosomes (i.e., a woman). By Stark's rules this is discrimination, not medicine, and such a conclusion is simply a *reductio ad absurdum* refutation of his rules.

As a whole, this book is extremely difficult to read. At first I thought that I was dull, or that I was missing some profound reasoning, untutored as I am in the field of political science and unspecialized in the therapy/enhancement debate. But I think the problem was not mine. Only after reading and re-reading hundreds of pages can one distill and assess the exact rules Stark is prescribing. Confused as they are, I have tried to state them clearly and succinctly above; I wish the author had done the same early in his book.

The book is also filled with idiosyncratic jargon that makes it unnecessarily hard to follow. For instance, readers must continually remind themselves what Stark means by "a conflict of curve." Hardly a term of art in philosophy, political theory, or medicine, a Google search of all of cyberspace for the exact phrase "conflict of curve" yields only the Table of Contents for this book. When discussing the notion of "cultural genocide," he coins the phrase "cultural spouse" to describe a metaphorical cultural counterpart of a medical condition. In a confusing mix of metaphors, physical blindness has a "cultural spouse" in the metaphorical "blindness" by which certain persons are described in our culture. Somehow this is supposed to mean that eliminating blindness as a medical condition would not result in "cultural genocide" and thus would be morally acceptable. Adding to the confusing jargon, it turns out that there are not just "cultural spouses" but also "cultural siblings." He talks about one medical condition "encompassing the same acreage" as another, and urges readers to "reverse the arrow" when he intends that we should look at the question the opposite way. Chapter 2 is called "A Visit to the Kantian Doctor," but it has

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nothing to do with anything Kant ever said, nothing in the Kantian corpus is quoted to support that title, and by the end I still had no idea how I would recognize a Kantian doctor if I ever met one.

Stark is certainly grappling with an important and difficult set of issues. Even the President's Council on Bioethics has demurred at the thought of setting limits for medicine by pursuing the enormously difficult task of distinguishing between therapy and enhancement. But Stark approaches the question wearing a straitjacket woven from the presuppositions of the liberal academy, and hence is compelled to attempt a Houdini routine.

In searching for something that might pass for objectivity, Stark can't conceive that there might be an alternative source of objectivity beyond the distribution of phenotypical traits in populations. Compounding the problem, he repeats a mistake made by many others. He conflates biological normality with statistical normality. Since statistical normality could only result in arbitrary cut-points, and given the value he places on individual autonomy, he is compelled to contrive the befuddling (and befuddled) hybrid of individual subjectivity, social inter-subjectivity, and arbitrary assertion that he presents in this book.

But there is another way to think about human beings and human medicine. If we construe disease as a purely subjective notion, then the only possible limits to medicine's reach would need to be imposed by the arbitrary and subjective will of others. Yet by engaging in a philosophical anthropology, we might be able to give some philosophically justified answers to some of the pressing questions medicine faces. Elsewhere, I have defined a disease as a "class of states of affairs of individual members of a living natural kind X, that disturbs the internal biological relations (law-like principles) that determine the characteristic development and typical history of members of the kind, X,... [whereby] at least some individuals...are, by virtue of that state, inhibited from flourishing as Xs." Nothing in this definition precludes Xs from changing over time. Nothing in this definition says that there are no variations in the distribution of phenotypical traits in a population of Xs. But to flourish as an X is not the same as deciding, subjectively, what flourishing means for me. If X is the human, then the problem facing medicine may not turn out to be so much a "conflict of curve" as it is our culture's wholesale, deliberate, and ultimately perplexing agnosticism about the nature of our humanity.

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