

Distrust, Social Justice, and Health Care

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Abstract

What steps, if any, should be taken to eliminate the distrust that many racial minorities feel toward the health care system in the United States? Is this distrust an issue of social justice or should it be viewed as an instance where people unreasonably fail to take advantage of existing opportunities? I argue that this distrust is an issue of social justice and that the state does have an obligation to eliminate or mitigate it, especially in the area of public health. **Key Words:** African Americans, AIDS, distrust, health care, justice, racial discrimination, medical ethics, Tuskegee Syphilis Study.

MOST PEOPLE IN THE UNITED STATES consider health care, along with food and housing, to be “primary goods.” According to John Rawls, one of the leading political philosophers of the 20th century, primary goods are things that every rational person is presumed to want (1). These goods have value to a rational person no matter what his or her plan of life might be. In his important books *A Theory of Justice* (2) and *Political Liberalism* (3) Rawls argues that the allocation of these goods is subject to the constraints of justice and that processing these goods has a bearing on a rational person’s self-concept. The cornerstone of Rawls’s account of social justice is his belief that the least-advantaged members of society, as measured by their possession of the primary goods, should be the gauge by which we judge the justness of the basic structure of society (4).

Because of his belief in this “gauge,” Rawls endorses redistributing resources by taking some from those who are better off, if doing so will make the least-advantaged better off than they would be under any alternative arrangement. However, Rawls’s critics from the political right contend that egalitarian/welfarist conceptions of justice violate the individual’s right to liberty (5). And his critics on the left claim that his commitment to equality does not go far enough (6). They argue that the needs of many, especially the

working class, will always go wanting in a capitalist mode of production.

As we can see, there are various ways of conceptualizing the demands of justice. In this paper, I will not explore the general question of what the correct account of distributive justice is. Instead, I shall ask whether the distrust that racial minorities, particularly African Americans, feel toward the health care system is indeed an issue of distributive justice.

Demands of Justice

No matter which account of distributive justice we embrace, when we say that an institution or practice is unjust we believe that this fact gives us a compelling reason for altering or abandoning that institution or practice. Since justice is considered to be the first virtue of social institutions, injustice demands action. The action demanded can, and often does, involve state intervention.

In capitalist societies like the United States, with a constitution that vests rights in individuals, great weight is given to individual liberty. Individuals are allowed to pursue their own conceptions of the good provided they respect the rights of others. In such a system, justice demands that we respect the rights of individuals. On any account of rights, rights violations provide us with a strong motive for change, a reason for feeling sympathetic toward the victims of such injustice, and a basis for claiming that the victims deserve to be compensated.

Discussions about what should be done now in response to the recently overturned system of legal racial discrimination have led to contrary conclusions. Some people argue that state-sanctioned

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tioned racism is a thing of the past, that racial minorities should forget about that past and work to take full advantage of present opportunities (7). Others argue that vestiges of the system of legal discrimination still exist, and that racial minorities will not be able to develop their skills or reach their full potential until our society takes further steps to break down the barriers that have been created by a long history of racism (8). The position that one takes in this debate will bear directly on where one stands regarding minority distrust of the health care system.

For those who think we ought to put the past behind us, it is hard to imagine why minority distrust of the health care system should be seen as an issue of social justice. For those people who view things exclusively in terms of a current time-slice, our horrible racial history does not justify giving additional resources to racial minorities for the purpose of addressing their present distrust of the health care system.

On the other hand, those who think that this history is relevant to public policy believe that society must address this distrust as a matter of social justice, because distrust is a clear consequence of racist practices that were perpetrated or condoned by the state. For these people, affirmative action and compensatory education programs may also be necessary to bring about social justice.

Others believe that a just society does not have to try to compensate the descendants of members of racially oppressed groups, but that the good or just society has forward-looking reasons for taking the steps necessary to make itself more egalitarian and open to all. These people are not concerned about identifying wrongdoers and providing compensation to those who have been wronged. They focus instead on the good utilitarian reasons for providing resources to persons and groups that need them (9).

Distrust

Before I comment on the justness of this distrust, I would first like to say a few things about the nature of the distrust that certain racial minorities are said to feel toward the health care system. For the sake of brevity, I will limit my focus to African Americans. I also do so because African Americans are often cited as the group that best illustrates this skeptical attitude toward the health care establishment. This skepticism raises two questions: Is the distrust that African Americans are said to feel rationally grounded? If the distrust is in some sense irrational, does this mean that a just society is under no obligation to address it?

Let me begin with the second question. The mere fact that many African Americans distrust the health care system does not mean that the system is unfair to them. Nor does it directly follow that the system ought to be altered or abandoned. This depends upon why, in some sense, they distrust the system. If this distrust is based upon misconceptions, then one may initially think there is no need to change the system.

But this initial reaction may be mistaken. Just because a system is fair does not mean that it can readily be seen to be fair. Part of what we mean by a good health care system is that it is perceived to be good by those involved with it. This is why systems analysts are concerned to produce systems that are simple and readily accessible to the general public. The fact that a system is fair may not be good enough. It may also be necessary that the system can be readily viewed as fair by the general public.

A health care system that wishes to be responsive to the needs of the entire community may have an obligation to address even the erroneous perceptions of the system by African Americans. Even if the system is just and the distrust is not well founded, the long and troubled relationship between African Americans and various components of the health care system may make the distrust that many African Americans feel understandable if not justified. Given our history, perhaps an equitable health care system should be willing to make reasonable efforts to dispel these feelings of distrust. As Aristotle said, the equitable person is not a stickler for justice, especially when doing so does not serve the wider demands of morality (10).

But what should count as reasonable efforts in such a situation? In my view, two factors have to be considered. One important factor is how much this distrust affects the delivery of good health care to African Americans. Another important factor is the extent to which the costs associated with eliminating this unfounded distrust would divert funds from medical needs that may be more pressing. An equitable health care system must be willing to address these factors in a candid and public way. Doing so would make it clear to all involved that the system is concerned about the interests of the whole community, and that it is sensitive to the historical context that gave rise to this distrust.

The Duty to Eradicate Distrust

From a moral point of view, why should a just society cater to the false perceptions of a large segment of the African American population?

One might argue that an action that is not in itself immoral can be described as morally faulty if it closely resembles an immoral act (11). Immanuel Kant's argument against the mistreatment of animals is often cited as an instance of this. Kant claims that we have duties not to be cruel to animals because this type of cruelty will undermine the genuine duties that we have to persons (12). Although treating animals in a cruel manner does not violate Kant's categorical imperative, such treatment damages our benevolent feelings and makes us prone to be cruel to persons. Resemblance is taken to be a morally relevant feature of our actions because it can corrupt the actor and it can also mislead others in ways that lead to their moral corruption.

Does the resemblance argument have any application to the debate over minority distrust and the delivery of health care? Perhaps it does. If efforts by public health officials intended to reduce the risks of AIDS in predominantly African American communities resemble the strategies that were used in the now-infamous Tuskegee Syphilis Study (13), then those efforts, although not in themselves morally wrong, may be faulty because of their tendency to corrupt the actors or those who witness them. In the 40-year Tuskegee Study, there were 399 black men with syphilis and 201 controls. The unwitting participants were not exposed to syphilis by the researchers, but they were not treated for it either. Even after the discovery of penicillin, the syphilitic men in the study were not informed about their condition, nor were they treated. In order to keep the participants ignorant, there was an extensive collaboration among a variety of government agencies, private institutions, and community-based organizations. If public health programs resemble, in form but not in content, the practices in the Tuskegee Study, then this might give pause to many people in poor black communities.

Sensitive public health officials have attempted to design programs to address the distrust in poor African American communities. However, strategies like hiring "grassroots" people from the community can backfire and further contribute to the distrust because such efforts often resemble what happened in the Tuskegee Study. The Tuskegee Study used culturally sensitive techniques on the grassroots level to ensure the involvement and participation of the subjects.

Even if we assume that the resemblance argument applies to acts of individuals, it would not follow that institutional behavior which resembles immoral acts has the same effects. In fact, my intuitions about institutions are not clear. Philosopher Julia Driver has argued that one basic

reason for thinking that acts that resemble immoral acts are faulty is that we may be unsure about the moral status of these acts (11). Because we are unsure, we tend to play it safe and regard these actions as morally faulty. Can we justify calling public health programs in African American communities morally objectionable because they appear objectionable to members of these communities? Some would argue against such a characterization. They might contend that to do so would be unreasonable. Are they correct?

Whether they are correct depends upon how confident we are about the safety and fairness of these programs. As the probability of their being safe and fair approaches certainty, we are inclined to reject the misgivings that African Americans have about these programs. But when the evidence of safety and fairness is not convincing, African Americans' misgivings will require greater attention. What will count as reasonable will depend upon people's past experiences, the likelihood and extent of the possible harm, and the resources that are available to cope with any bad eventualities.

But Driver also argues that there are sometimes good consequentialist reasons for refraining from doing something that is not in itself wrong. She cites the case of a woman who pays for a vase that she knows she did not break to forestall any of the negative consequences that might result from a misunderstanding concerning the broken vase (11). Similarly, a public health care system may expend funds to forestall unjustified misgivings that may result from misunderstandings about legitimate efforts to reduce the risk of AIDS and other communicable diseases. Even though there may be some negative consequences connected with pandering to people's false perceptions, the good consequences are thought to outweigh them.

There may be a more compelling argument for using state resources to mitigate the bad consequences created by an understandable, but unreasonable distrust of the health care system. John Rawls has argued that stability is an important component of a just society. According to Rawls (14),

[t]he problem of stability is not that of bringing others who reject a conception to share it, or to act in accordance with it, by workable sanctions, if necessary, as if the task were to find ways to impose the conception once we are convinced it is sound. Rather, justice as fairness is not reasonable in the first place unless in a suitable way it can win its support by addressing each citizen's reason, as explained within its own framework.

In other words, Rawls recognizes that in order for a society to be just, citizens and public officials must comply with the rules laid down by the basic institutions of society. This compliance must be sustained over a period of time, and those who are expected to comply must feel that they have a reasonable basis for doing so. For Rawls, it would not be permissible to coerce, pressure, or trick citizens into this compliance. Stability must be achieved by addressing each citizen with persuasive reasons.

A society in which a significant number of persons believe that they are being treated unjustly will be unstable. Society, therefore, has an obligation to demonstrate that it is indeed just in order to achieve reasonable citizens' cooperation with its rules and procedures.

Many African Americans believe the health care system in the United States is not designed in accordance with principles that are publicly recognized as fair and just. If stability is important, and I think that it is, then a just society should be willing to expend resources to demonstrate the justness of the system. This is especially important where there has been a history of isolating a segment of society by race and then treating this segment in unfair ways. Since African Americans have experienced such a history, it is only reasonable that they would be skeptical about the kind of treatment they might be accorded. Special efforts will be required to overcome that skepticism. We need not go overboard and pander to unreasonable attitudes.

It is also important to note that past denials of rights have not always flowed from malevolent motives. Sometimes, attitudes that give rise to unfair treatment of African Americans have been more thoughtless than calculated. But, while we don't want to encourage wild conspiracy theories about state-sanctioned programs of black genocide, we also don't want to be too cavalier in our attitudes about the possibility that African Americans may be the victims of injustice. We have made great strides in race relations in this country, but there is still much work to be done. As a just society, we must be willing to make special efforts to ensure that African Americans can have confidence that the basic institutions of their society will respect their rights and treat them with dignity.

The Source of General Distrust

Does this mean that we should alter or abandon crucial parts of the health care system? If we are to fairly answer this question, then we need to realize that the systemic distrust that African Americans are said to feel is not limited to health care, but is part of a more general distrust of pub-

lic and private institutions that have a tainted history of dealing with black people (15).

The past policies and practices of these institutions have certainly played a role in engendering this distrust. No one can seriously dispute the host of serious injustices that have been committed against African Americans by the criminal justice and health care systems, simply because they were black. But the critics would argue that these things were in the past and that *de jure* racial discrimination has been either eliminated or greatly reduced. For African Americans to continue in distrust is for them to adopt a crippling "victim's mentality." This attitude is said to prevent many African Americans from taking full advantage of existing opportunities (7) and to encourage many to blame their personal failings on racism.

Is this criticism valid? I don't think so. According to the philosopher Laurence Thomas, we must exhibit a minimal degree of trust of strangers without adequate evidence of their trustworthiness (16). But this is true only in situations that are not life threatening. When they are in danger of significant bodily or economic harm, rational people require strong evidence of the trustworthiness of the person or institution they are to rely upon. To the extent that this is true, African Americans have good reasons for skepticism about our health care system.

Does the continued existence of anti-black racism, as documented by scholars like Andrew Hacker, in his book, *Two Nations: Black and White, Separate, Hostile, Unequal* (17), undermine the belief that African Americans are treated fairly by institutions that are controlled by whites? Does this position assume that all racism must be eliminated before African Americans can drop their skeptical attitudes? Perhaps what is necessary is not the total elimination of anti-black racism, but racism that results from racist intentions. But, as our experiences with the desegregation of schools have shown us, the elimination of intentional racism is not enough (18). *De facto* racial discrimination can be just as debilitating as *de jure* discrimination. And, as we are well aware, efforts to eliminate *de facto* segregation from the schools and other walks of life have met with strong opposition. This opposition is seen by many African Americans as evidence of the lack of good will toward African Americans. If they are right, then there is a rational basis for many African Americans to be skeptical about how they will fare when they seek health care.

But even if African Americans are justified in thinking that their race could adversely affect the quality of care and attention that they will receive

in the health care system, this would not show they are, in fact, being treated unjustly unless the system does not attempt to eliminate their distrust. It is not enough to make health care programs available to African American communities. Additional efforts and resources should be made available to these communities to overcome the skepticism that many members of the community have toward these programs.

The 40-year Tuskegee Study is, unambiguously, a case where people's rights were violated. It is also a case that gives even the most secure African Americans pause about what their government might do in the name of maximizing the common good. This study has planted in the minds of many African Americans the belief that the state may think it is permissible to adopt questionable means with African Americans if the ends are honorable enough. The similarity of strategies used to recruit and retain participants in the Tuskegee Study and in HIV education and risk reduction programs reinforces that belief (19).

The Tuskegee Study and the disproportionate impact that AIDS is having on the black community help to fuel conspiracy theories about black genocide. These theories in turn breed distrust in a population that is poor and resentful in the wake of persistent inequality. Given that the present political and social reality was created in large part by the unjust past actions of the state, state action to alter this reality is warranted. Whether one uses the language of rights or the vocabulary of the common good, special efforts by the state are required if public health programs are to overcome an atmosphere of distrust that took years to create. We should not be surprised to find that engendering trust cannot be achieved overnight.

Aside from the distrust of public health efforts to combat contagious diseases, we also find widespread distrust about the quality of primary health care that poor African Americans receive. Given the changes that have occurred in black communities in the wake of racial integration and the growth of a black underclass, we find fewer black professionals to serve a population with serious health care needs.

Given that trust is an important ingredient of a good doctor-patient relationship, it is especially urgent for members of the black underclass to have a trusting relationship with the people who provide them with health care (20). It is not that the doctors are generally unwilling to develop this relationship, but, given that these patients often don't see the same doctor on a consistent basis, the familiarity that is necessary to build the bonds of commitment between doctors and patients is often lacking. As

the old family doctors knew, the human side of medicine may be as important as technical facility. The lack of familiarity and the consequent lack of trust, influences many poor African Americans and dissuades them from seeking health care.

This distrust and the harm that results from it cannot be addressed without making fundamental changes in the way we as a society conceptualize our obligations and priorities. And we cannot make these changes without first reaching some public consensus about how to eliminate the remaining vestiges of a system of racial discrimination. A consensus about the requirements of justice is probably the best that we can achieve in a democratic society defined by racial and cultural pluralism and a belief that each citizen is entitled to shape his or her own conception of the good life.

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