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The Significance of Injustice for Bioethics

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Leslie P. Francis

In their *Principles of Biomedical Ethics*, Beauchamp and Childress famously listed justice at the end, behind autonomy, beneficence, and non-maleficence. They were explicit that this listing was not meant to suggest prioritization, but this is what seems to have happened over the years in the teaching and practice not only of bioethics but of other fields in applied ethics with which I am familiar.

There are many explanations for how justice has tended to come last. Justice isn't a single principle, but a topic area in social, political, and moral philosophy. There is deep disagreement about which principle(s) of justice to adopt, and why. By comparison, there is not deep disagreement about which principle of non-maleficence to adopt (although there is disagreement about what counts as "harm" for the purposes of applying non-maleficence). Moreover, justice finds its home as a characteristic of social institutions, although it may also be used to characterize individual relationships. In Rawls's characterization, for example, justice is the first virtue of social institutions. By contrast, many of the issues in applied ethics fields deal with relationships between professionals and their clients. Even business ethics deals with questions about individual action, such as lying, loyalty, or responsibility. For my purposes, what is important is that these issues about

individuals and their relationships are treated first, rather than being situated within a framework of justice.

It is thus not surprising that many texts in fields such as bioethics, engineering ethics, business ethics, and even environmental ethics treat justice as something of an afterthought. It may appear in chapters about access to health care, the social responsibilities of business, or engineering and public welfare, or in environmental justice units on discrimination and the location of polluting factories. But justice is much less likely to appear as the overall ethical framework within which other issues in the field are situated. Instead, the other issues come first, treated outside of any framing justice might provide. When justice does appear, moreover, the most likely selections are from Rawls's *A Theory of Justice* (1971) and Nozick's *Anarchy, State, and Utopia* (1974). These works, while surely setting the stage for discussions of justice over the ensuing 45 (yes, 45!) years, have been followed by many important, more recent developments. These rarely make their way into texts for teaching most applied ethics courses. They are even less likely to make their way into bioethics courses.

Both the marginalization of justice and the failure to consider much recent work are, I believe, deeply unfortunate. They are unfortunate in both directions:

bioethics has much to learn from these developments, and these developments could well be tested and problematized in the context of bioethics. These developments are also very useful teaching tools—an aspect I shall emphasize as of particular interest today. So, let's delve briefly into three theoretical developments in the post-Rawlsian space that I think are particularly important but that are too frequently off the radar screen in many bioethics texts and discussions:

--the discussions of luck egalitarianism

--the development of relational egalitarianism

--and, the evolution of non-ideal and partial compliance theory

Luck Egalitarianism

Rawls developed his view as a theory of justice for basic social institutions. But it quickly came under criticism as a theory about distributional end states, initially from Robert Nozick in *Anarchy, State, and Utopia*. Rawls's veil of ignorance experiment was premised on the assumption that differences in skills and talents, economic and social conditions, and the like were arbitrary from a moral point of view. As such, Rawls argued, they should not be able to influence basic institutions for distributing the benefits and burdens of social cooperation. Nozick argued that Rawls could adopt this view only at his peril: Rawls, Nozick wrote, "can succeed

in blocking the introduction of a person's autonomous choices and actions (and their results) only by attributing everything noteworthy about the person completely to certain sorts of 'external' factors. So denigrating a person's autonomy and prime responsibility for his actions is a risky line to take for a theory that otherwise wishes to buttress the dignity and self-respect of autonomous beings." Here began so-called "luck egalitarianism": the idea that inequalities resulting from poor fortune are unjust, but inequalities resulting from poor choices are not.

Inequalities in access to health care lie at the cusp of the interaction between bad luck and bad choices. On the one hand, genetic endowments, epigenetic changes, and social determinants of health are bad luck. Distributions of access to health care that fail to address inequalities resulting from these factors would be unjust. On the other hand, ski injuries might appear the result of poor choices, so perhaps it would not be unjust if people were expected to pay for knee-repairs. Early on, luck egalitarians noted the interaction between choice and luck: between poor choices and their outcomes lies a great deal of luck. Many individuals make what some argue are choices: to smoke, to have unprotected sex, or to avoid a flu shot. Only a proportion of these will get lung cancer, become pregnant, or catch the flu. So these health outcomes are neither pure luck nor pure choice.

A number of health policies may be informed by, or pose difficult issues for, luck egalitarianism. Consider just these examples: what should be included in minimal essential coverage? Who, if anyone, should be expected to pay copays or deductibles as they access health care? Should premiums be adjustable for individual behavior such as smoking, participation in wellness programs, or engagement in risky activities? Should factors such as location or history of alcohol abuse affect access to the scarce resource of liver transplantation?

In a paper published in 2006, Nir Eyal posed counter examples to standard versions of luck egalitarianism. I present versions of them here that are adopted for access to health care. First, Hero and Inconsiderate. Hero sees a burning building and rushes into it to save a child. Inconsiderate wakes up in the middle of the night to find his house on fire due to lightning. Both suffer similar burns. Had Hero not run into the burning building, he would not have been injured. In all other respects, such as ability to purchase insurance, they are the same. On standard luck egalitarian accounts, Inconsiderate's injury would be bad brute luck but Hero's would be bad option luck. So the disadvantages of Hero's injury are unjust but the disadvantages of Inconsiderate's are not. But Hero's bad fortune

seems unjust and surely does not reflect the desert considerations of primary concern to luck egalitarians.

Eyal's second example is called Acceptable and Saintly. Acceptable lives in an area of the US where Zika infection is unlikely. Acceptable could have moved, but does not, because of the costs and inconvenience of moving. Saintly, however, does move, for the sole reason of avoiding Zika—and indeed is the only person who does move. Soon after, a mutation in Zika results in widespread infection in both locations, which Acceptable and Saintly both catch. Would it be just for Saintly to be compensated for the damage when Acceptable is not? On some standard luck egalitarian views, Acceptable's choice to incur the risk would count against compensation, so Saintly would have the stronger claim. Again, Eyal thinks, this is counter intuitive: not every choice to incur risk should be viewed as vitiating claims for compensation. (Think: having intercourse while using highly effective forms of contraception, or walking outside alone at night.)

On Eyal's view, these standard versions of luck egalitarianism are misguided because they fail to take into account whether the choices are culpable. There is something to this view. For example, people who deliberately choose not to get health insurance when they could easily have afforded it might be regarded as

having chosen culpably. It may also help unmask some of the judgments that lie behind students' and others' intuitions about whether alcoholics should be deprioritized for liver transplants, unmarried women should be held responsible for pregnancies even if they used highly effective contraceptives, and people who do not try to exercise or lose weight should bear some of the health costs that may result. Some of the judgments students make may rest on assumptions about whether any of these behaviors are culpable.

But there is much that is problematic about Eyal's view, too. There are questions about the availability and difficulty of alternatives, such as how much someone can be expected to give up to purchase health insurance or how far someone can be expected to travel to attend a weight loss class. There are questions about internal constraints that affect choices, such as depression. These questions also may be mediated by the presence of injustice, my third topic today. They surely are not easy to resolve, but they are at the heart of many health policy debates today. Having students consider luck egalitarianism's insights and difficulties can help them to see what is at issue in these debates.

Relational equality

Recognizing some of the difficulties with luck egalitarianism, Elizabeth Anderson argued in “What is the Point of Equality?” that focusing on distribution as a question of compensating for bad luck—who gets which opportunities, resources, benefits, and the like—is mistaken. Instead, she defended a form of relational equality, in which the fundamental question is the role of equality in ending oppression. She understands oppression politically; one way to translate it into health care is to consider how decisions are made: political decisions about the structure of health care systems, institutional decisions about the structure of care within institutions, and even decisions about patient care within the context of provider patient relationships.

Here, let me use autonomy as an illustration. As autonomy is often presented, it’s described in terms of respect for individual choices. For choices to be respected, people must not be coerced and must have decision making capacity. People are coerced if they are subject to unjustified threats of force and perhaps also wrongful denial of rights or justified moral claims. (Think: refusals to provide obstetric care without acquiescence in sterilization after delivery.) People have decision making capacity if they have at least a basic understanding of their values, their conditions, their treatment options, and the risks and benefits of these options; and if they are able to apply this understanding to realize their values, at least in some

rudimentary way. Thus understood, the exercise of autonomy is a matter of individual choice. Autonomy is not seen as primarily relational, much less as located within a web of power relationships. But this is to frame autonomy narrowly and in abstraction from the social contexts in which it is exercised.

Take discussions of managed care or, more recently, accountable care organizations and whether they may fail to demonstrate respect for patient autonomy. Ethical concerns raised about these forms of care delivery in terms of patient autonomy are whether they present patients with a reasonable set of options or whether they unjustifiably ration care. Concerns also include whether they are sufficiently transparent about the motivations that may affect physician decision making about care options or whether they conceal economic incentives that present conflicts of interest. These forms of care delivery are seen as threats to autonomy if they unjustifiably limit options or information. Only very occasional discussions have considered the political power relationships in how these care structures are organized. Oregon's effort to expand Medicaid eligibility and paying for it by ranking the care that would be covered was seen as an example of deliberative democracy in action. Some of the original health maintenance organizations such as Group Health of Puget Sound were seen as models of patient participation in deciding coverage. But I have seen very little if any serious

political philosophy address how these organizations are structured or whether the power relationships within them are problematic from the perspective of patient autonomy. Similar points could be made about the delineation of essential health benefits for purposes of the Affordable Care Act.

To be sure, there is frequent mention of the vulnerability of illness as a threat to autonomy. But this vulnerability is seen primarily as individual deficiency, not as a structural issue about the organization of health care. On the level of individual patient care, shared or supported decision making may be brought in to address failures of individual autonomy. But these structures are viewed as substitutes, rather than being seen as integral to autonomous decision making itself.

Accountable care organizations are supposed to put the patient at the center of a network of integrated care and to be accountable (to whom? Patients? Or payers?) for improved care quality. According to NextGen HealthCare, a service provider to accountable care organizations, “Now imagine this . . . healthcare providers across the country, from primary care doctors and specialists, to hospitals and large health systems, are all collaborating and coordinating care with each other to improve outcomes for their patient populations – and getting paid well in return.” Descriptions such as this at best put the patient at the center as the object of care.

They do not consider questions such as how to decide which collaborations matter, what count as improved outcomes, or how very well paid physicians should be.

Here, bioethics has much to learn from a centerpiece of disability rights advocacy, “nothing about us without us.” And here, too, bioethics confronts several different aspects of non-ideal theory: the natural misfortune of illness, the impact of unjust social institutions, and the ethical difficulties that arise when recognition of duties of justice is uneven.

Non-Ideal and Partial Compliance Theory

John Rawls famously introduced the distinction between ideal theory and partial compliance theory in *A Theory of Justice*. (1971) While theorizing about justice for ideal circumstances, Rawls recognized that different approaches might be needed where either natural or social circumstances were less than ideal. Non-ideal theory treats issues such as how progress can best be made toward justice, what injustices take precedence to address, what strategies are likely to create new roadblocks to overcoming injustice, or what are the obligations of individuals or institutions when others continue to behave unjustly. (Cohen 2000; Miller 2011). This last—

what to do when unjust behavior is fairly widespread—is specifically partial compliance theory.

Rawls didn't see the need for non-ideal theory as a problem about ideals, but as about whether real world circumstances were such that ideals could reasonably be applied to them. Within the past ten to fifteen years, discussions in political philosophy of non-ideal and partial compliance theory have burgeoned. Like Rawls, these discussions, largely see the problems as lying with existing circumstances, not with the construction of ideals. For example, Zofia Stemplowska, in "What's Ideal about Ideal Theory?" sees ideal theory as "theory that fails to issue recommendations for how to improve our society that are applicable for us here and now." She thinks theories that assume full compliance (and thus are inapplicable to present circumstances) can still be useful because they provide a standard against which to judge whether comparatively we are taking steps towards the ideal and to have a picture of what an ideal might look like. On these views, ideal theory remains the touchstone and it seems reasonable that this should be the primary focus of inquiry. Problems of how to get towards the ideal are problems of transition that hopefully will pass. Or, they require attention to what individuals should do as a matter of fairness when others are not doing their

share: should they try to make up for others, just do what would have been their fair share, or give up if partial efforts will not solve ultimate problems.

An alternative, however, is that there are difficulties in the formulation of ideals themselves. Amartya Sen (2009, 2006), for example, emphasizes the importance of comparative rather than transcendental theories of justice. Sen argues that theories of justice need not take a complete or totalist form for many reasons, including information gaps, difficulties in judging among considerations that have a dimension of weight, or the need to make political room for areas of agreement or disagreement among different points of view. A major driver of Sen's approach is his view about the limits of social choice and the ability of decision procedures to yield partial but incomplete agreement.

I agree with Sen that the problem lies in part with ideals, although my starting places are somewhat different than his. As I see justice, it is a matter of ongoing work at inclusion and flourishing: what next steps, at individual or social levels, will enable individuals in all their differences to do well at what matters to them? In my view, a picture of ideal justice might be so abstract as to be vacuous, so fuzzy as to be unrecognizable, or perhaps even positively misleading.

Here, universal health care in the US is a useful example, which Sen uses. Seen comparatively, the US is a more just society if it includes more people receiving funding for health care appropriate to their conditions and choices, when others are already receiving similar care. To make judgments of this kind, we do not need a complete picture of what a fully just health care system would look like. Indeed, given developing technology, changing understandings of the nature of disease, the ever-shifting world of disease itself, and conflicting demands on social resources, we may not be able to say what a fully just health care system would look like. Idealization might tempt us to say: it would be a system in which everyone got the greatest amount of needed health care possible under the circumstances. But this idealization might be vacuous—what *is* this greatest amount?—or, more disturbingly, it might lead us into a situation (not so unrecognizably like the problems we have today) wherein everyone might think that getting more health care for themselves is a matter of urgent justice, when it might not be comparatively more just at all.

Expanding inclusion addresses what would be incremental improvements in the justice of social institutions involved in health care. Another kind of non-ideal problem is that of partial compliance: how to address circumstances in which some are behaving in ways that have come to be recognized as unjust. On the

provider side, admittedly controversial examples might be the failure to provide accommodations for patients with disabilities or the refusal to accept at least some share of patients funded by Medicaid reimbursement rates. On the patient side, again controversially, we might want to consider whether decisions not to participate in the shared costs of health insurance coverage are unjust. Seeing these decisions as partial compliance questions frames them as problems of participation in furthering justice, as part of a justice as a social project. That's a different frame from more common ones in terms of whether the restrictions on liberty that may be imposed are justified in order to avoid free rider problems or even to distribute burdens of compliance fairly. It forces us to ask how decisions by some to opt out might impact comparative improvements in justice in the sense of fostering inclusion in the circumstances in which we actually live. That's a very different question from whether those who opt out take unfair advantage of those who do not, much less whether in an ideally just world the freedom of individuals to opt out would be recognized.

Conclusion

Let me sum up. In my judgment, applied ethics is ineluctably non-ideal and partial compliance theory. It's ethics in the context of unjust institutions and conduct.

Theorizing or teaching about concepts such as autonomy in abstraction from this recognition is misleading. Instead, questions such as how to realize autonomy should be framed in the context of incomplete justice. There's much to be learned from the past nearly 50 years of discussions of justice to help with this enterprise, but they are too little known or discussed in much contemporary bioethics.