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FROM THE EDITORS

ARTICLES

This packed edition of your Philosophy and Medicine Newsletter provides some rare treats for our APA membership. In addition to three papers from the Eastern Division's panel "Understanding Health," we include two papers from two sessions on "Health, Healthcare and the Contemporary World" sponsored by the Society for Philosophy in the Contemporary World, and two papers from the October 2011 meeting of the American Society for Bioethics and Humanities (ASBH)—as well as a few book reviews and a poem.

Michael Boylan in his paper "Health as Self-Fulfillment" explores different perspectives on health, depending upon the subject position taken. Anita Silvers in "Too Old for the Good of Health?" points out that different conceptualizations of health have an impact on what services are provided, then explores the effects of that on one population, the aging. Rosemary Tong's paper, "Ethics, Infertility, and Public Health: Balancing Public Good and Private Choice," read in her absence by session chair Leonard Kahn, pursues a similar line in connection with issues of reproductive health. The subject of several articles in past issues of the *Newsletter* as well, what "health" is, and what to do about it, continues to perplex.

In group meetings which converged with our interests, Mandy Mitchell, in her paper "Hegemony and the Health Care Debate: A Post-Marxist Analysis," directs attention to one contemporaneous health care issue: the acrimonious political controversy surrounding the Patient Affordable Care Act, in an analysis that has wider implications for our forthcoming election. In "Is Choice Good or Bad for Justice in Health Care?" David Chan moves the question of patient autonomy from the bedside to the wider context of contrasting political views of distributive justice. Two more papers from the society's presentations will appear in the next issue.

Two philosophers regularly appearing in these pages presented at the annual meeting of ASBH, and James Lindemann Nelson and David DeGrazia have kindly allowed their papers there to be printed in this issue. DeGrazia in "Disability and Disadvantage Through the Lens of Value Theory" suggests that disabilities, while more than mere "differences," are not the sole determinant of quality of life; and in "Enhancing Persons, Commodifying Bodies" Jim muses on some implications of Michael Sandel's position on enhancement technologies for the contested question of paying for organs.

As well as a sardonic poem by Felicia Nimue Ackerman, the issue includes a review by Lauren Milner of *Emperor of all Maladies* by Siddhartha Mukherjee, and Deborah Barnbaum reviews *Rethinking the Ethics of Clinical Research* by Alan Wertheimer.

Comments, suggestions, and contributions welcomed.
Mary V. Rorty and Mark Sheldon, Editors

*Health as Self-Fulfillment*¹

Nothing is better than a diligent life.

Ancient Roman adage

Michael Boylan
Marymount University

Let me begin with a little story.² There was once a king named Agamemnon who was a general in a foreign war (on behalf of his brother). The war lasted a long time. When he finally returned (with a princess from the losing side who was now his concubine) he was killed by his wife (who had a consort of her own). The principal reason that Clytemnestra gave for killing Agamemnon was that he killed their daughter Iphigenia out of sheer necessity dating back to a dispute with Artemis. In the middle of this tragedy Zeus comments:

It is true that man's high health (*hygeia*) is not content with limitation. Sickness (*nosos*) chambered beats against a common dividing wall. It is human destiny to set a true course in life, yet this course may be dashed against the sudden reefs of disaster. (Aeschylus, "Agamemnon" ll. 1001-1007, my tr.)

So what are we to make of our little tale? From the beginnings of the Western tradition in ancient Greece *health*, represented by the goddess *Hygeia*, stood within a context.³ She was the daughter of Asclepius (god of medicine—who himself was the offspring of Apollo). Her siblings were *Eros* (god of love and directed desire), *Peitho* (goddess of eloquent persuasion), *Panakeia*, (goddess for all curing), *Iaso* (goddess of remedy and recuperation), *Akeso* (goddess of recovery), and *Aglaea* (goddess of natural beauty). *Hygeia* attended her father Asclepius (god of medicine) and palled around with *Aphrodite* (goddess of love, beauty, and sex). One day they had a feast to honor *Hygeia*'s birthday. What began as panegyric for *Hygeia* quickly devolved into a dispute. Each sibling wanted *their* natures to be honored the most. This escalated into a fight concerning who Father Asclepius loved best and who was grandfather Apollo's favorite. Each sibling made his or her case (based upon their natures), but there was no agreement and in the end the party degenerated into a disaster as everyone exited—everyone except poor *Hygeia*, whose feast it was!

What a sad story. But dry your eyes, the tale has a message: *Hygeia* (health) is not best understood by *any* single sibling. Instead we must understand health via a multi-layered presentation. Certainly, medicine is about assisting us all toward good health. This means that the *aim* of medicine is promoting

health. Thus, “health” is the foundational concern in medicine and medical ethics. But “health” means different things in different contexts. There have been several popular paradigms that have been advanced in recent years about health. These can be roughly grouped into two categories: (a) a public health approach based upon some group allocation of goods that are primary to human agency, and (b) a more subjective approach based upon some understanding of well-being.⁴ Let’s take a quick look at these and then move toward one particular understanding of subjectivism.

Public Health Approach

A very popular guest at Hygeia’s party in modern times is the group perspective. Some authors such as Amartya Sen have conjectured that public statistics on group longevity say something about how happy and capable people are within a society (Sen 2009). Figures about infant mortality, morbidity due to certain types of disease, epidemiological data on who the sick are, and many common forms of causation yield important information on community health. Individuals in the community can be protected by evidence-based medical responses, but the focus is upon the group.

There are at least two ways to understand the public health perspective on human health. Neither perspective is clinical, with a focus on the individual and the physician. Instead, the focus is upon groups of people and maintaining environmental conditions that will minimize the spread of infectious disease via clean air, water, sanitation, vaccination, and access to basic medical care. This can be called the thin theory of public health. It is largely based upon prudential self-interest understood collectively. There is another vision of public health that extends this vision to basic human rights—such as those enunciated in the United Nations Universal Declaration of Human Rights. This can be called the thick theory of public health. I have been an advocate for the latter vision and believe that its broader mandate can only be supported by an appeal to normative ethics (Boylan 2004-b).

The difference between these two approaches is that the thin theory of public health views a person as healthy if she isn’t ill (defined as having known bacteria or viruses attacking the body causing a loss of function leading to diminished productivity in the workforce). This is often extended in the thin theory to include workplace injury, accident, and response to war and natural disaster. This viewpoint concentrates upon negative physical influences of various sorts upon the body and its physical systems—viewed collectively via an identifiable social/community group.

In contrast, the thick theory sets out that there is more about being healthy than merely being not-diminished by one’s physical systems—viewed via an identifiable social/community group. More is needed to demonstrate public health: namely, various educational opportunities, human rights, and the ability to participate in one’s community as an equal partner and to be able to strive towards one’s vision of a life fulfilled (Boylan 2004-a).

What the public health approach (in either of its two forms) has going for it is that it identifies groups of individuals within a context. There are natural and social environments in which we all live. While the thin theory focuses upon the natural environment, the thick theory combines the social and the natural contexts that permit individuals to act purposively according to their vision of the good. By focusing upon target groups, social changes can positively affect health within that target group. Darrick Tovar-Murray completed a small demonstration project to show the truth of this conjecture. Now it is correct that the context is not everything. One can live

in an area that has a cholera outbreak and never get cholera. One can live under a repressive dictator and never get jailed for being an agent provocateur. Just because one lives in a bad natural or social environment does not ensure that he will be a victim. What these deleterious environmental conditions do is to increase the probability that something bad will occur that will affect one’s ability to execute purposive action. The public health perspective is thus important because it *can* affect the context of our action.

However, we must be clear that it does not guarantee it. One may have a relatively good natural and social environment and still fall prey to a fatal disease or be the victim of an unjust action. As was argued above, we are working in the land of statistical probabilities.

There is something very appealing about seeing health via the public health guest to the party (thin, thick, or governed by social choice), but this perspective is general: often good for policy, but possibly inaccurate for individuals. It is one important perspective, but as we have seen, there are many guests at this party.

Subjectivist Approaches

The last class of party goers would be those who represent subjectivist approaches. These include the advocates of well-being broadly understood and well-being understood via the lens of self-fulfillment.

Well-being is a term that is used variously in different contexts. Derek Parfit suggests that there are three sorts of theories in this category: (a) *hedonistic theories*, (b) *desire-fulfillment theories*, and (c) *objective list theories*. The first path to well-being is merely to seek what one perceives will make her happier via some calculus that is made through a preference-hedonism model (cf. the public health preference model above). If X is thought to bring about more happiness than Y, X is preferred over Y. The very fact that the agent chooses X over Y indicates that the agent thinks that X will deliver the most happiness/pleasure. The criteria for this preference are calibrated via the personal worldview of the individual. Thus, Freud near the end of his life might prefer to forego pain-killing drugs in order to maximize mental lucidity. This is a hedonistic calculation based upon Freud’s personal theory of value (Griffin). Such an account is relative to the chosen personal theory of value. Unless one has created meta-ethical value criteria to steer the process, it is subject to very wide relativistic swings—some of which are in direct contradiction.⁵

In *desire-fulfillment theories* the model works this way: we should seek a course of life that will fulfill as many desires as possible. Parfit calls this approach the *success* orientation. The agent decides for himself what approach will yield success and thus fulfillment of as many desires as possible (thus ensuring well-being). In the context of health, one might choose to be an exercise enthusiast because undergoing that strategy can satisfy more physical desires than any other alternative. However, this could be turned on its head if I turn out to die from an inherited disease (despite my careful exercise routine). The very structure of the *desire-fulfillment theory* is such that it operates on a conditional “p => q” structure (if p then q). However, if this model is faulty (as in the exercise example), then the conditional becomes contingent. This means that achieving the state “p” does not guarantee “q” (invalidating *modus ponens*) which also implies that one can fail to achieve q (~q), without assuming ~p (thus invalidating the logical rule of *modus tollens*). There may also be multiple ways of achieving q without invoking p. If “p= 2 hours daily of vigorous exercise” and “q= not being sick from a bacterial/viral source or subject to an organ failure,” then it is easy to

see that one might exercise and not stay well in the sense of *q*. Also, one might be well in the sense of *q* and not exercise. The reason for this harkens back to the objective functionalist theories of health discussed above.

Objective list theories seek a paternalist path toward well-being. Under this approach one acts according to a set of criteria that are generally agreed to lead to the fulfillment of as many desires as possible (thus ensuring well-being). This is very much like the success model of the previous paragraph except that the origin of the strategy is in commonly accepted maxims. However, the problem raised with the exercise example would still hold here. The only real difference is the origin of the strategic approach. However, when thinking about health, we can think about the difference between these approaches as one in which first the agent chooses his path that he thinks will yield as much happiness as possible. The source of the strategy is a list of value priorities and factual understandings as found in the personal worldview.

In the second case the source of the strategies lies outside the agent—as well as the values and facts concerning the world (for example from the family physician). The agent then chooses to follow a regimen that is generally thought to improve one's chances of achieving “*q*.”

There are many advocates of well-being as a way of understanding and achieving health. However, there are some detractors, too. One important attack on well-being as a master value comes from Thomas (Tim) Scanlon.⁶ Scanlon distinguished three uses of “well-being”: (a) the basis of individual decision-making (1st person), (b) the basis of a concerned benefactor's action (3rd person), (c) the answer to the “why should I be moral” question (1st person). The first sense amounts to fulfilling desire. But rational choice (which should undergird theories of morality) cannot be based solely upon fulfilling desire—even rational desire expressed as a preference (see above). This is because of the connection with well-being that lacks the requisite boundaries. Enter self-fulfillment.

Self-fulfillment

Self-fulfillment in the guise of functionalism has been raised before in the health debate (Allmark). This approach is generally tied to an understanding of Aristotle's *eudaimonia* as functionally “good souled” (where *soul* indicates a natural capacity of the human person, e.g., rationality). The idea of being “fulfilled” presupposes a standard that one works towards. The closer one gets to the terminus, the more fulfilled she is. The million dollar question is: “What is the standard for *homo sapiens*?” Unless this question is answered, the self-fulfillment question devolves into the well-being question with all its various mazes of interpretation.

In this essay I connect health to self-fulfillment as understood through an analysis of the personal world view. My assumption is that in life we all strive to achieve our vision of the good (Boylan 2004-a). I have written much on the personal worldview. The personal worldview is a compilation of all one's understandings of the world factually and normatively. If one follows my suggested structures for the worldview (Boylan 2004-a), then I contend that as a first order metaethical theory it would give direction to how one would live his life. As I show elsewhere, I believe that this position dictates that everyone adopt cooperative theories of justice first in holistic ways of looking at the world (Boylan 2004-a, 2011). Let's examine these claims in relation to a common objector position.

The most common objector is one who thinks that life is just like Thomas Hobbes' state of nature. Those who hold this world view will be suspicious of those who are possible competitors. The vision of being penniless on the street is

constantly before the holder of this worldview as the worst case—*yet possible* scenario.

For Hobbes the metaphor is of a state of nature (forest, hill, and dale) in which all are equal—though not identical (e.g., you may be able run faster than I, but I'm stronger than you: in the end the sums are equal). Because of this summative equality, and the fact of scarcity of resources, the result is that there is fierce competition that will inevitably lead to continual strife (war). This is the human condition according to Hobbes and is depicted via his state of nature metaphor.

Another fellow traveler is Friedrich Nietzsche who seeks to describe the basic psychological nature of human kind in order to give a causal account from the agent's point of view.

Suppose, finally, we succeeded in explaining our entire instinctive life as the development and ramification of *one* basic form of the will—namely, of the will to power, as *my* proposition has it . . . then one would have gained the right to determine *all* efficient force univocally as—*will to power*. The world viewed from inside . . . it would be “will to power” and nothing else. (Nietzsche)

For Nietzsche, the will to power is a psychological fact that finds metaphorical expression in *Beyond Good and Evil* and *On the Genealogy of Morals*. In some respects it is a deeper account than Hobbes' because it gives specification of *why* we are acquisitive. It is because, at base, we are psychological egoists whose quest in life is to exert whatever influence we can upon the world. There is a trust that those who can assert the most influence will also be driven by a love of nobility (beauty) that will keep them in check from being utter tyrants. Of course, skeptics of the regulative power of nobility (beauty) will see this depiction as one that devolves to mere *kraterism* (“to each according to his ability to snatch it”). Under this sparser interpretation, Nietzsche falls into the tradition of the hunting/war metaphor. (The more generous interpretation would put Nietzsche on the edges of the metaphor, given the tempering force of nobility [beauty]).

In either case “the will to power,” as metaphorical expression, is seen in the context of other writers who assert the same thing. Like Hobbes, Nietzsche can be connected to a vision of life on earth as a competitive contest. We are all engaged in seeking to extend ourselves over our environment and over others.

One practical consequence of the hunting metaphor of life is *laissez faire* capitalism. We all strive to gain the goods, and the science of economics is created to describe (and not prescribe) the process. Since everything is all wrapped up tight in a theory of human nature, what could be more correct? *This metaphorical expression measures our goodness in terms of competitive acquisition of goods—money, status, and power. Thus, our primitive drive to be good is satisfied by the garnering of these goods in the highest amounts. The individual with the biggest heap at the end of the day is the winner!*

If self-fulfillment is a legitimate guest at Hygeia's party, then the competitive model suggests one measure by which we can assess whether we are healthy: how much power have we achieved via competition within our frame of reference. The more power, the healthier we are. If one accepts that self-fulfillment is a legitimate way to understand health and if the best candidate for the scorecard is power, then that clearly follows.

In contrast to the highly competitive personal worldview paradigm, I would put forth an alternative model:

The Cooperative Goodwill Thought Experiment

Imagine that each of us is on a quest to be good. We are seeking a means to be good that will make our world (and us) better through intellectual excellence (theoretical and practical reason) and emotional excellence (love), i.e., establishing the good will within ourselves. The quest may last a long time. The quest may end in failure. It is up to us to do our best to seek and obtain the object of the quest. In the process of our quest we may be required to undergo various ordeals and tests of our resolve and worthiness. It is the nature of human existence to sally forth on this quest and do our individual best at achieving the reward (though we may be humbled, scorned, and ridiculed in the process). This process thus represents a prescriptive view of a good human life. To be healthy is to be closer to the endpoint in the quest. The closer we are, the healthier we are.

In the thought experiment an alternative is set forth to the competitive worldview standpoint: the cooperative worldview standpoint as exhibited by the focus upon creating a good will. Though expressed differently in both Aristotle and Kant, it holds that we ought to try to acquire various excellences in character that would create habits in us such that our decision-making apparatus (our will) would become increasingly good (as measured by our internal assessment via the personal worldview imperative).

There are several reasons why each of us should prefer the cooperative personal worldview over the competitive worldview—especially concerning health. First, there is some medical evidence that being hypercompetitive can lead to several serious deleterious medical conditions (Freidman, Haukkala, et al., Al-Asadi). Second, the nature of the competitive worldview is a zero-sum game while the cooperative worldview is not. The very nature of the competitive worldview is that there are limited goods sought after by many. It is much like the child's game of musical chairs. There are four chairs and six children. They walk politely around the chairs while the music is playing, but when the music stops, it is a mad dash for the chairs. Children are pushed away as the hyper-aggressive win the day. Is this the community worldview we wish to promote? Will this lead to general public health? I think not. It will lead to a society of a few super-winners at the expense of the many. Such a worldview violates the personal worldview imperative because it violates the affective goodwill and the inductive understanding of consistency—as such it violates this first order metaethical principle. In addition, I have argued elsewhere that such an outcome is inherently unjust (Boylan 2004-a).

So let's suppose that we proceed with a cooperative personal worldview that is in accord with the personal worldview imperative. What else is necessary to proceed along a path of health as self-fulfillment? To answer this, I would again foray to the ancient Western world and the biomedical writers—particularly the Hippocratic writers and Galen. What these writers found to be the case was that *balance* was the most critical factor to health. By balance they meant of course the balance between the four humors of the body: blood, phlegm, yellow bile (sometimes serum), and black bile (Gill, Hankinson). Of course, Aristotle advocated balance, too, in his doctrine of the mean (and so did Confucius with his concept of *li*—balance presented via the metaphor of dance). What these ancient writers understood was that an essential key to health is balance because it encourages the development of *sophrosune*, self-control (a master virtue when considering balance). Self-control is also crucial in achieving self-fulfillment. This is because deciding what wants to do in life (constrained

by the personal worldview imperative) is a process of reflection, self-control, and habits of excellence. These three menu items work together so that one can act autonomously toward a worthy goal in a balanced manner. The process looks like this:

The Self-Fulfillment Approach to Health

1. One seeks balance to achieve self-control—basic fact of human nature
2. Self-control allows one to more successfully carry out the personal worldview imperative (reflection that leads to the rational and affective good will)—Assertion [A]
3. A developed rational and affective good will allows one to develop habits of excellence that are directed toward one's chosen life plan—A
4. A life plan chosen as per above will be the most choice-worthy path toward an agent's life goals (self-fulfillment)—1-3
5. Because the process begins with balance, B, this property continues through all the steps as a property of the agent—Fact [F]
6. Balance supports personal health—5
7. The choice-worthy path toward self-fulfillment supports personal health—4-6

What this approach to health offers is a subjectivist approach that has an objective structure (the personal worldview imperative) that can alleviate the common objections to well-being (the most prominent subjectivist theory discussed). Because of this, I think that it offers the best subjectivist understanding of health.

Conclusion

This essay began with Hygeia's party on Mount Olympus. There were many guests, each of whom had a legitimate reason to be there; there were no counterfeit invitations. I have applied this literary conceit to discuss the problem of health pluralistically—showing the proper roles of various perspectives, but also arguing that none of them gives a complete account.

From the point of view of most readers of this essay, the most personally relevant understanding of health is subjectivist. In order to avoid the common complaint against well-being accounts as lacking an adequate external structure, this essay has set one in place within the context of self-fulfillment (within the context of the personal worldview imperative) and a personal measure of health as we lead our lives. In the end, we must judge ourselves after the lines of *The Eumenides* (the final work of the *Oresteia*):

*Home, home ever high aspiring,
Daughters of Night, aged children, cavalier processional
Bless these with silence . . .
There shall be peace between Pallas Athena and the
guests.
Zeus, all knowing, met with Fate to confirm it
Let us sing as we make our exit. (1033-1047, my tr.).*

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Endnotes

1. Versions of this essay and the accompanying essays of Silvers and Tong will appear in *Medical Ethics*, 2nd Edition (Malden, MA and Oxford: Wiley Blackwell, 2013).
2. This is, of course, my story, but it is loosely based upon Greek Mythology.
3. These relations are often parsed differently. This is because there are discrepancies among the primary sources. Since this is not an essay on philology, I will present these characters in the context of my initial story.
4. In the longer version of this essay, the functionalist approaches are also discussed.

5. I have created such criteria in Boylan, 2004-a (ch. 2).
6. Scanlon's argument on well-being works this way:
 1. There are three uses of 'well-being': (a) the basis of individual decision-making (1st person), (b) the basis of a concerned benefactor's action (3rd person), (c) the answer to the 'why should I be moral' question (1st person)—Assertion [A] (P. 108)
 2. WB 1-a is experientially important to us all—Fact [F] (p. 108)
 3. WB 1-a is sometimes understood as fulfilling desire—F (p. 113)
 4. Desire is not sufficient for rational choice—F (from Ch 1/ p. 114)
 5. Desire and its fulfillment cannot give an account of WB sufficient for morality—2-4
 6. Rational desire understood as preference is often put forward as a ground for WB—F (p. 116)
 7. The good is not dependent upon preference (informed desire) but the reasons that make it worthwhile—A (p. 119)
 8. Rational desires understood as preferences cannot give an account of WB sufficient for morality—6-7
 9. Some say that rational aims tied to WB create a motivation superior to desire—A (p. 121)
 10. [Motivation is important to morality]—F
 11. Fulfillment of rational desire(broadly and specifically) must be tied to WB or the desire wasn't rational—A (p. 121-23)
 12. Many rational desires have intrinsic aims (e.g., friendship and science) that are not connected to WB—A (p. 124)
 13. Though WB has some connections with rational aims, it is not the sole source of determination—9-12 (p. 124)
 14. WB 1-a does not have clear boundaries because it cannot account for why it is good—A (p. 127)
 15. There is no limit to WB 1-a—A (p. 129)
 16. [What has no limits has no boundaries]—F
 17. WB 1-a has a boundary problem—14-16 (p. 129)
 18. In choosing the best life, the 'most choice worthy' trumps 'well-being'—A (p. 131)
 19. WB is not primary and sufficient—17-18
 20. When one concentrates upon his own WB, he becomes selfish—A (p. 137)
 21. [Being selfish is bad]—A
 22. WB 1-a can be counterproductive—20-21 (p. 133)
 23. WB 1-a is not a master value for morality—5, 8, 13, 17, 19, 22
 24. WB 1-b is generally connected to morality via justice and benevolence, cf. Rawls and Sen—A (p. 139)
 25. A benefactor may act to promote a choice worthy life over one based upon WB (e.g., artist or labor organizer)—A (p. 135)
 26. WB 1-b implies a standard account of WB based upon promoting pleasure—A (p. 136)
 27. The boundaries between the benefactor's and recipient's WB are unclear—A (p. 136)
 28. The recipient does not have reason for merely promoting his pleasure—A (p. 136)
 29. WB 1-b is not a master value for morality—24-28
 30. WB 1-c would require one to justify moral principles on grounds that presuppose what people are entitled to—A (p. 137-138)
 31. Premise #30 involves a circular claim—F (p. 138)
 32. WB 1-c is not a master value for morality—30-31
 33. Well-being is not a master value for morality—1, 23, 29, 32

Too Old for the Good of Health?

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Introduction: Goodness and Health¹

Health is an important good of the highest priority. But is health an absolute or relative state? And is there clear agreement on what health is? The centrality of health's goodness is magnified by the commonplace idea that realizing the value of other basic goods depends on whoever seeks access to them being healthy first of all. And if health has such primacy both in itself and because of its effects, maintaining or improving people's health should take priority over other worthwhile aims. As a prudential personal policy, therefore, individuals should guard their health because health leads to other good things and because without health nothing else will seem good.

Moreover, the public policy prompted by this view about the importance of health appears to be that, above almost all other obligations, government must care about citizens' health. Consideration of justice in caring for citizens seems to decree that unless health is distributed equitably among members of the population, there will be unfair disparities in people's capacity to take advantage of the opportunities that living in a democratic society provides (see, for example, Daniels 2012, but also see Hessler and Buchanan 2012). This connection of fair opportunity to health usually is interpreted as mandating a policy of equitable distribution of medical services. Thus, a society's overall justness may be said to depend importantly on its citizens all enjoying effective health care.

One version of the foundational role for other goods that health is thought to play makes being healthy a sufficient condition for enjoying other beneficial states. Health is valuable not only in itself for the sense of well-being it provides to those who have it, but also instrumentally because valuable attitudes such as optimism, and admirable dispositions such as geniality, appear to be sparked by the combination of healthy body and healthy mind that constitutes the healthy human individual. In a different version of the foundational claim, health is proposed to be necessary, even if not sufficient, for other important goods. Having one's health has been claimed to be necessary for taking advantage of or enjoying other basic goods, whether these be material or intangible, personal or social.

Philosopher Lawrence Becker sums up this latter version of the primacy of health as follows: "Some level of good health is a necessary condition for almost everything we care about, both with respect to individual well-being and a sustainably productive, well ordered society" (Becker 2010, 11). Notice that Becker talks about health as if its quantity can be discerned, or at least the level of its presence measured, in individuals and in societies as well.

Becker's judgment reflects a familiar kind of evaluation about people's health. Individuals are compared as to their success in caring for their health. Those most effective in maintaining personal health are more likely to be sought after as family partners, as work colleagues, and as associates for collaborative civic engagement and play. Also, nations are assessed as to their populations' health status, and comparisons both between different nations' populations, and of groups within a single national population, are executed to identify disparities in levels of health among different groups of citizens. Societies that achieve the greatest collective level of health for their populations may be emulated or envied as the most desirable locations in which to conduct business or to reside. Societies with high population health that is distributed fairly

among different segments of the population often also are commended. Of course, such commendation is deserved only if individual citizens' levels of health are traceable not only to good genes or good luck, but to the just allocation of medical and other societal services.

Health thus is presumed to be a kind of thing attributable to individual persons, but also to collections of people like different economic or ethnic groups, or to entire nations. Health also is attributed to cohorts of different ages such as children and old people. But whether what counts as health remains constant throughout these different contexts is not clear. How can conceptualizations of health in infants and ninety year olds be reconciled, for example, when neither the biological states of the elderly and the very young, nor their prognoses, have much in common? Yet to be healthy seems equally a desideratum for both very old and very young people.

Philosophers thinking about medicine often append another seemingly commonplace idea to the conventional celebration of health as a central good. They take health (or more precisely, engendering, improving, and preserving health) to be the medical profession's aim. Public policy, the ensuing argument goes, should value health care services because health is a basic good. From the reputedly indubitable goodness of health, plus the dubitable hypothesis that more health care will cause more health, it thus has seemed to follow that respectable theories of distributive justice should give access to health care priority over other kinds of resources that people more readily could do without or would turn down. But we should not be lulled into thinking that the apparent lack of controversy about the goodness of health signifies consensus as to what health is, let alone about the distributions of health and health services people are owed.

Health – Neutral or Normative?

Health is both a neutral and a normative notion. In its neutral aspect, health refers to an individual's overall organic state. The processes that are conceptualized as creating the components of health may be narrowly construed as being strictly biological, or broadly construed as including social arrangements as well. In its normative aspect, conceptualizing health specifies or explains good health by delineating what constitutes the soundness of that state. Due to their normativeness, such ideas of health influence or have repercussions for health care policy and practice, including the political, economic, and cultural arrangements that position a health care system within society.

In regard to normativeness, there are several different ways of understanding how the idea of and facts about health can be a source of moral prescriptions, policy mandates, standards, and regulation. Some theorists take the normative dimension of health to emerge from the neutral one, hypothesizing that the vitality of the human organism is constituted by natural processes which maintain it at a close to optimal state as long as they work well. Here, neutral claims about human biology are presumed to be preeminent, with normative claims supposedly reducing to factual claims about biological optimality or at least not extending much beyond these. Other theorists believe that the normative dimension of the idea of health will pervade any attempt at a neutral one, in that social values inevitably are among the drivers for distinguishing biologically desirable from detrimental processes.

Accordingly, for thinkers of the latter persuasion, the normative component of conceptualizing health is enlarged while the neutral aspect shrinks. Here, the divisions between the organic conditions deemed optimal or pathological are held to be a function, at least in part, of diverse personal and social interests and policies rather than of organic processes

distinctive or destructive of a natural human kind. On this view, the apparently bright line dividing who is considered healthy from who is not comes from the placement of societal spotlights rather than from a natural inner glow.

Of course, only some of us appreciate health thoughtfully, while others do so as an afterthought. And there also are individuals who seem so uncaring or reckless about health that they voluntarily engage in behaviors that impose injury or illness on themselves or others. In some cultural contexts a collective tendency to condemn such individuals for not taking care of themselves prevails, even to the extent of customarily speculating that individuals who become injured or ill bear responsibility themselves for suffering such outcomes. In other cultures bad luck or fate is blamed.

Our current cultural context leads us to expect that health deficits can and should be fixed. Some of us rely on the medical profession to take the lead in improving the sophistication of public judgment about (un)healthiness, especially in regard to silent symptoms such as elevation of blood pressure or prostate-specific antigens. Others, however, object to the medical profession's inflating ordinary people's worries about being healthy, especially as such anxieties can be exacerbated by medical practice that designates comparatively low risk biological conditions as pathological and thereby demanding of prevention or cure. This kind of issue arises because of changing expectations about being healthy.

Definitions of Health

Various ideas of health have achieved prominence in the bioethics literature and influence in health care policy and practice as well. These represent different formats or structures for understanding this highly generalized concept that applies to diverse kinds of people whose situations vary enormously. In health care practice, certain tests or other evidence-based procedures may be designated as definitive in determining whether persons and populations possess health, and thereby are considered to fully capture what health is. But formulating a theory that advances a concept of health in the course of explaining biological or other phenomena might better support prediction, and thereby be more generally informative for comprehending what health is for people than any set of tests. And even more informative might be the addition of a viewpoint on the nature of health that is drawn from a theory of the place of health in our social as well as biological lives.

Adopting an understanding of health that is structured by one or a combination of these formats may require ignoring or ruling out some instances where ordinary usage would have it that references to health apply, but that are not consonant with a more narrowly refined definition. Concomitantly, a definition of health may be broadened beyond current usage, so that a larger proportion of an individual's dispositions—for example, inattention or sadness—are medicalized. Although an enlightening idea of health need not comport with ordinary usage to be suitable, its acceptability will be affected by the concept's normative commitments, which may be discerned by considering the impact of its adoption on health policy and health care practice. Of crucial importance in considering a particular idea of health is its prospective impact on health care justice, and specifically, whether policies and practices built on the proposed understanding of health will promote or impede equitable access to, and treatment by, medical services.

One prominent idea of health construes it as normal biological functioning. This account equates health with the "natural" functioning of the human biological system. Natural human functioning is delineated in terms of what is typical of the human species. On this approach, what is statistically typical

of the species, or of a sub-group of the species, is presumed to be optimal, or at least effective, for maintaining the species or the prominence of a sub-group within the species. Further, reports about individuals' biological condition as typical, which are statistical descriptions, are elided with judgments that the persons concerned are normal, evaluations that their biological components are properly formed, and their physiological processes are working well.

Within a conceptual frame centering on normality, people with unusual biological properties or traits are readily thought of as malfunctioning, in part because a popularized (mis) understanding of evolutionary development throws suspicion on atypical biological conditions as being maladaptive. So what is advanced as being a detached scientifically descriptive approach to defining health turns out to be a covertly partisan criterion that imposes the functional modes standard derived from the most populous or otherwise dominant kind of human, on everyone else. Historically, such seemingly "scientific" definitions have been applied to condemn females and racial minorities, among others, as biologically defective.

A second prominent approach to defining health is openly, rather than stealthily, normative. An example of such an account is embedded in the aspirational policy that guides the mandate of the World Health Organization, a United Nations agency charged with pursuing "the attainment by all people of the highest possible level of [health](#)." The WHO constitution defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO 1948). According to views like this, we should not think of health as merely the organism's natural biological state undisturbed by disease. Instead "health is a positive concept emphasizing social and personal resources, as well as physical capacities" (WHO 1986).

Notice that the WHO definition attributes both biological and social components to health. Initial attempts to explain the role of social factors conceived of these mainly as causes that directly depress or support individuals' biological condition. For example, the social factor of poverty leads to personal lack of food and the resulting starvation of people does direct biological damage to their bodies' cells. As thinking about the idea of health grew more perspicacious and nuanced during the last part of the twentieth century, however, acknowledgement of the influences of social organization became a presupposition of the concept.

To illustrate, as the journalist David Bornstein has observed, "Many health care professionals are aware that social conditions affect health more than medical care does" ("[Treating the Cause, Not the Illness](#)," NYT, an excerpt July 28, 2011 <http://opinionator.blogs.nytimes.com/2011/07/28/treating-the-cause-not-the-illness/>). Another reason for recognizing the social dimension of health was the observation that in social contexts favoring one-size-fits-all arrangements, biologically atypical individuals are much more likely to suffer constricted capacity to function and to have their biological condition labeled pathological than in one that responds to people's biological differences with flexibility, inclusive access, and support. An example is the inherited condition *adermatoglyphia*, labelled the "immigration delay disease, caused by a so-called disease allele that is an unstable version of the *SMARCAD1* gene (http://www.nlm.nih.gov/medlineplus/news/fullstory_115031.html; <http://www.smartplanet.com/blog/rethinking-healthcare/fingerprintless-mutation-causes-8216immigration-delay-disease/6126>). This allele causes affected individuals not to have fingerprints, which makes them dysfunctional, but only for purposes of obtaining proof of identity documents such as those needed to cross national borders. No other loss of function

is attributed to this genetic condition; nevertheless, it has been diagnosed as a disease.

Over the decades the WHO has expanded the sophistication of the approach to creating definitions by constructing classificatory systems that recognize the interaction of biological and social factors. The International Statistical Classification of Diseases and Related Health Problems (ICD) codes for diagnoses of pathologies and abnormalities, as well as evidence of diseases and injuries and their social circumstances. The International Classification of Functioning, Disability and Health (ICF) categorizes components of functional and dysfunctional states. Within the ICF framework, personal capacities and incapacities are cast as resulting from complex relationships among individuals' health conditions, their personal agency, and the accommodating or exclusionary nature of their physical and social environments.

These classifications, as well as others developed by various nations and by international organizations, are used for, among other purposes, measuring health outcomes to assess the comparative effectiveness of health care programs. Computing the size of the health improvements that alternative health resource allocation projects are likely to achieve is proposed to resolve such policy questions as which kinds of disease prevention efforts to deploy, which segments of the population to try to cure, and which governments are performing the best in regard to their population's health. The details of, as well as any general thesis embedded in, each definition of health influence the amount and kind of medical or rehabilitation care provided to people whom that definition designates as currently or prospectively unhealthy but as able to benefit from treatment.

In sum, what a society thinks health is affects not only who receives services, but also which services are received. Given the impact of how health is conceptualized on decisions about whose health merits care, we should be concerned with the details of whatever idea of health drives the distribution of medical resources. Normative definitions are conventions that go beyond biological fact to serve the social and political purposes of organizations that adopt them. Defining health in such persuasive ways suggests that nature endorses certain policy directions and practical choices.

To illustrate, statistical definitions invite the pathologizing of all individuals whose biological constitution does not accord with the common pattern. Adopting this sort of definition of health encourages dismissing individuals who are shorter, slower, or sadder than the standard for persons, or are otherwise biologically anomalous, as being too ill or impaired to participate productively in social activities, at least until they are medically or surgically altered to approximate normality or in some other way fixed. This way of thinking in terms of biological homogenization rationalizes standardization of work places, educational processes and social components, as those whom biology has not made to fit the supposed template for healthy humanity are deemed defective and therefore not eligible for social opportunity.

Another problem plaguing many normative definitions arises from disagreements about the propriety of broad, or instead narrow, definitional scope. Proponents of conservative conceptualizing argue that confining what constitutes health to biological conditions alterable by pharmaceutical, surgical, electrical, or similar manipulations of body parts focuses health care policy on problems remediable through medical intervention. They object to broader definitions that, they complain, conflate being healthy with that feeling of overall well-being that can elude even the most species-typical individuals. Proponents of expansive conceptualizing, on the other hand,

argue that successfully cultivating health in people calls, at the very least, for nourishing, sheltering, and educating them, and organizing them into satisfying community roles. These two points of view clash in practice about such choices as whether promoting health demands dispelling unhappiness with pills, and whether medical insurers or instead school districts should be the providers of the behavioral instruction that may be therapeutic for autism.

Disputes of these sorts are rooted in people's divergent values about responsibility for health; they therefore cannot be resolved simply by shifting around non-normative components of the definition of health. To use such a definition, decisions about relativizing the standard it sets to cohorts and contexts must be made. For example, what assumptions about the effect of economic conditions should be incorporated into the concept so as to constrain interpretations of observations that signify health? Should the standard be applied differently in dissimilar economic contexts, so that prosperous and impoverished populations may be judged equally healthy despite differences in the levels of energy and initiative their people show? Or may contexts diverge sharply in regard to people's access to material goods without affecting the application of the standard, so that the lower levels of energy and initiative of populations deprived of nutrition, shelter, and similar sustenance may be judged unhealthy because compared with the higher levels of more economically favored peoples?

Each choice about relativizing the concept has its own policy and practice impacts. On the first of these choices about selecting context, economically disadvantaged populations will be deemed healthy, even if their energy and initiative do not rise to the standard of people in privileged populations. In other words, if the standard for judging whether a particular impoverished population is healthy is based on the levels of energy and initiative typical only of poor people generally, a poor population is more likely to seem healthy than if its members' energy and initiative are compared to the levels achieved by much better nourished and rested people.

Why limit the comparison of signifiers of health to poor people this way? Characterizing a population as healthy may be favorable for economic development that needs a supply of reliably healthy workers to attract private investment. So in this scenario a conception of health that contextualizes the judgment of population health just to a comparison class of people with similar economic status is beneficial as a marketing tool to try to remedy impoverishment.

On the alternative scenario, however, comparison of the same impoverished population with the higher levels of energy and initiative manifested by a dissimilar because economically privileged people results in the former group, which has sharply lower levels due to having little to eat, being designated as unhealthy. Why structure the comparison this way instead? Characterizing a population as unhealthy may procure international assistance, including nutrition supplements, from better off nations and international organizations like the WHO. In a scenario different from the first one, being designated as an unhealthy population may be beneficial because an alternative strategy for obtaining resources is to be played out.

Ideas of health, and the standards for wellness they contain, therefore can vary in virtue of the comparison classes they invoke. Such definitional differences will affect the aims for which each conceptualization of health is applied, as well as how different kinds of people are judged in regard to those aims. The next section, which explores how conceptualizing health influences elder policy and practice regarding the aged, will illustrate in more detail issues that arise in the course of

applying an idea of health that has impact on policy and practice to a nondominant segment of the population.

Oldness

As the U.S. demographic swells with a growing proportion of old people, what constitutes health for elders, and what health care should be provided for them, have become aggravated questions. The 70 million baby boomers (born 1946-64) soon will double the number of Americans over the age of sixty-five. The boomers were the largest cohort in U.S. history at the time of their births. Within two decades, boomers will join the “old old,” people eighty-five and older. This fastest growing segment of the population is second only to children in needing care (Fishman 2011).

The unprecedented increase in the number of the elderly has been attributed to increased use of medical technology to extend senescent lives. Boomers’ life span (the longest length of time humans have been known to live) is not predicted to be lengthier than earlier generations. But successful campaigns to reduce early death have increased their life expectancy (the average number of years to be lived by a group of people born in the same year). Life expectancy for a generational cohort grows when fewer members of it die young. Preventative medicine such as vaccinations against infections like measles, smallpox, influenza, and polio reduced the number of deaths in the boomer cohort, as did campaigns for early detection of disease and against contamination of air and food by noxious substances. For example, in just the quarter century from 1985 to 2010, campaigns against smoking are calculated to have saved more than 50,000 lives in California alone (PIRE, 2010). Laws requiring buckling into seat belts also have increased life expectancy, one of several factors that have diminished accidental mortality in the generation born just after World War II as well as younger ones.

Many such commendable efforts have combined to maintain the extraordinary size of the boomer cohort from childhood till now, when its members are entering the late stages of life. The boomer generation’s numbers overwhelmed public education systems when its members started school in the mid-twentieth century. Now that they are becoming old, these same boomers are poised to stretch the medical care delivery system beyond current limits and perhaps beyond its capacity.

As a population cohort, the old may be deprived of financial resources and lack group medical insurance coverage because they no longer are employed. Private insurance plans would raise premiums based on advancing age because the risk of needing health care services increases after old age arrives. In contrast, the approach taken by public social insurance is that young people pay into the system through taxation while they are working and then in return the system pays out to provide medical care for them when they become old. Were it not for public plans that permit workers to pay into a system in order to provide for health care later, after they have ceased to work, many elders would find themselves unable to continue to afford medical care at the time of life they may need it most. But some people worry that the size of a retired boomer population may put sustaining health care for all of them beyond what the public system can pay.

In the face of such an increase of people seeking medical services, is it reasonable to expect that late life should be a time of healthy living? Or are aged individuals demanding medical services merely “greedy geezers”? That is, does provision of health care to old people who need it impose unfair burdens on the young by consuming health care resources that, even if enormously generous, cannot effectively enable elders to enjoy the good of health? (For more on the “greedy geezer” argument, see Francis and Silvers 2010; Rorty and Silvers 2011.)

In contemplating this conflict and considering the ethics of resolving it, at least two troublesome matters about elder

policy must be resolved. Both arise from lack of clarity about the interaction of biological and social components in conceptualizing health and assigning health status. Both are exacerbated by the resulting lack of consensus about defining what constitutes health for old people.

When Is Old Age?

The first problem is to identify the boundaries of the aged population. When does old age start? Perceptions of being old vary with people’s point of view, as thinking that someone is old can be affected by chronological standpoint. In a survey of U.S. adults, respondents as a whole said old age begins at sixty-eight years. But the subset of survey respondents over sixty-five years said old age begins at seventy-five years old, while the subset of respondents under thirty said having lived sixty years marks the start of being old (Arnquist 2009).

Should being old be defined instead in terms of individuals’ biological condition rather than their total years of life? Biological changes associated with being old include wrinkles due to loss of elasticity of the skin; grey or white hair or loss of hair; reduced hearing, vision, mobility, flexibility, agility, reaction time and balance; deficits in cognition including memory; and diminution of reproductive function. At the cellular level, there appears to be a correlation between shortened telomeres and aging.

Telomere length does not match up consistently with chronological age, however. Telomere extension may be possible, having been demonstrated in laboratory mice and nematode worms. In regard to other biological changes associated with old age, not every individual undergoes these changes at the same time in life. Nor is every biological decrement associated with aging equally debilitating for everyone. Some people, for example, are devastated by the appearance of silver hair while others glory in it. Similarly, some people regret reduced reproductive capability while for others the change is liberating. Further, progress in such research fields as regenerative medicine (to replace worn out or injured body parts with new organic ones) and bioengineered prosthetics (to manufacture non-organic replacement body parts) promise to make more and more bio-engineered corporeal renewal available. Thus, modern medicine may place retrieval of youthful functional capacity within the reach of the old, if the price for such restorative medical services can be paid.

Biological markers alone thus seem too inconstant to signify definitively the line beyond which old age lies. So how, if not purely biologically, to characterize the group of people who are old so as to define this population? There is great variation in how biological senescence affects human activity and achievement. But people generally acknowledge old age to have set in when, along with their advanced years, they experience curtailment of social functioning. In other words feeling old or being treated as old seems to happen when people age out of productive social roles.

To illustrate, in sub-Saharan Africa men often are counted as old when they are fifty years old and women at forty-five. As in industrialized nations, old age is here defined mainly in relation to work identity. Where work roles demand youthful capacity for great physical exertion and stamina, people are likely to be considered old at an earlier age. Also, and especially for women, being viewed as no longer executing a reproductive role often prompts being designated as old. In the early nineteenth century agrarian Western nations also tended to take fifty years as the onset of being old, while today in these same but now industrialized places, being counted among the old usually occurs no earlier than age sixty or sixty-five because this is when eligibility for the benefits of retirement pension schemes most often begins (WHO 2011). We may expect,

therefore, that policies to raise standard retirement from the work force to age seventy or beyond, now being proposed in order to shrink the number of individuals drawing retirement benefits and to enlarge the number for whom payroll taxes are collected, will result in a redefinition of the time when being old begins.

In sum, neither chronology nor biology is a stable signifier of the onset of old age. When old age arrives is a movable number that is far from a purely natural one but instead results in some part from cultural, economic, and political arrangements. The nature of each society's productive roles, and the availability of health care that can keep people executing these roles, are two social factors that affect the designation of membership in the elderly population.

Health in Old Age

In addition to the puzzle about the age when being old starts, a second problematic matter has to do with how unhealthy the old are. As a generalization, old people no longer in the work force are more frequent consumers of health care than young workers. That is to say, a larger proportion of this cohort than of younger ones uses medical services, although not every old person does. For example, the over-sixty-five cohort is over-represented with three times the proportion of seniors among the top 5 percent of health care dollar users in the nation as in the total adult population.

This is understandable because high medical expenditure is somewhat less concentrated, but not ubiquitous, among those over sixty-five than among younger people. Almost half the medical expenditure for all under age sixty-five patients is spent on the most expensive 5 percent of that patient population. In contrast, only about one-third of the health care expenditures for over age sixty-five patients is accounted for by the top 5 percent medical services users (AHRQ, 2006; Schmid 2007).

In view of these distribution statistics, the following claim appears to be an overstatement: "When we reach age 65, we consume health care resources at about 3.5 times the rate (in dollars) that we do prior to age 65" (Daniels 2012). The comparative data are for the collective health care costs of entire cohorts, not for the personal costs of each old individual. The health care costs of an individual who has reached age sixty-five need not be higher than the costs that individual expended earlier. Further, while health care costs for the old as a group cost 3.5 times more than for the young in 1985, by 2004 they declined to 3.3 times and still are trending downward, with the largest decline for any age cohort being for the age eighty-five and older group (AHRQ; Schmid).

A captivating idea urges old people to pursue a program of successful aging. To age successfully is to prevent disease, maintain full function, and contentedly execute the activities of an admired social role. But this prescription too easily can promote expectations of not aging at all. It is hard to escape advertising that invites elderly men to keep medication for erectile dysfunction on hand so they are instantly ready to perform sexually whenever the opportunity presents itself. Such portrayals suggest people need not change when they grow old and their health in old age should remain as it was in earlier phases of life. If elders remain in the same health states as younger people, they will not use health care with more frequency than they did in youth.

On reflection, however, this program proves deceptive. Like the components of any well-used mechanism, people's physical components wear out, buckle, or warp or otherwise deform. Medical services may delay such degeneration, or replace deteriorated parts, and possibly the patient's renewed

productivity may offset the price of treatment. Eventually, however, the promise of effective renewal must fade away, which revives the challenge of understanding health in old age. Indeed, the Roman philosopher Cicero famously contended that there is a special character to health when one becomes old. Upon feeling discomfort, distress, dizziness, or pain, younger people ordinarily ask how long before they feel well and what steps will hasten healing. But not the aged, for whom, according to Cicero, such feelings characteristically induce fear that their last days are about to arrive (see Mothersill 1999 for an insightful discussion of Cicero and other philosophers on the subject of old age).

For the aged, therefore, having one's health cannot be having the health of younger people, so what, for them, can having one's health be? For working age adults, health is understood in terms of species-typical biological functionality in the performance of staple social roles. For children, health can be related to the same standard, measured in terms of their potential to develop biological functionality rather than to current possession of it, as well as their potential to execute adults' social functions when they have matured sufficiently to do so. But biological functionality appears to decline rather than develop for the old. Being old is identified with ebbing strength, eclipsed optimism, depressed initiative, and doubts about personal worth. Conjoining this characterization of being old with the definition of health in terms of species-typical biological functioning designates being old as a time of losing one's hold on the good of health.

Elderly people also suffer deprivation of social functionality, as when aged individuals are retired from activities of social contribution and remanded to dependencies reminiscent of childhood. Further, for the old the resilience to maintain stability both in one's self and for one's environment also is assumed to slip away. In sum, none of the familiar conceptualizations of health provides space for allowing health to be a good available for the old as well as the young, as for all these versions the functionality of individuals in the former population is measured by a standard that compares them to young people's functioning and finds them wanting.

Goodness of Health for Old Age

That familiar ideas of health are biased in this way exacerbates the controversy about the strength of old people's claims to health care. If the characterization of health as inconsonant with old age prevails, elders cannot be owed their health as there can be no obligation to provide old people with what they cannot have. And if, just because they are old, health definitively eludes the elderly, health care services for them must be seen as ultimately ineffective, which inflames complaints that expending resources for their health care is wasteful.

Adopting a formulaic account of health that compares old age to youth disparagingly leads to a call to reduce medical services for the old. No doubt such reasoning will be found persuasive in some quarters, and especially to policy makers whose strategy for lowering health care costs is to label some groups of medical services users as undeserving. Thus has the "greedy geezer" grievance aimed at old people been fueled and the flames of resentment against this part of our population fanned.

Yet the reasoning deployed to motivate the "greedy geezer" complaint is suspect. Defining a minority population invidiously so as to make its members seem undeserving insults justice. Similar distortions infamously have been introduced by wrongly invoking misrepresentations of women and racial and other minorities to manipulate policy and practice. Standardizing health by reference to the biological

functions and societal roles that typify humans in mid-life similarly misrepresents people whose lives have passed that point. Health care practices built on this wrong idea need to be reshaped around a conception of health that is fair to people when they are in mid-life but remains fair to them when they have grown old. What change(s) can be made in our understanding of health so as to conceptualize the health manifested in old age not as an evil but as a good?

Two emendations of our thinking about health suggest themselves here. Both link elder health to achieving new ways of functioning, one emphasizing biological process while the other focuses on social positioning. Perhaps unexpectedly, therefore, both equate the good of elder health with functioning anew. Both foreground as valuable adaptive shifts in modes of functioning, which are rare in young individuals but common when people reach old age.

How does biological functionality manifest in old age, a stage of life when individuals are at higher than species-typical risk of encountering impediments to their usual modes of functioning? For this population, there is greater motivation to adopt or adapt to alternative modes. Recognizing this characteristic of the elder cohort is crucial for constructing a portrayal of health in old age. Such a picture must distinguish dysfunctions attributable to physical or cognitive deterioration from the disabling disorientation that often is their consequence, for these are different states. Adaptation to the former by assuming a new functional mode is a key protection against falling prey to the latter. While decline from species-typical physical and cognitive midlife functional levels may be an inescapable aspect of life for the old, displacement from the kind of healthy living appropriate for their time of life does not necessarily accompany such functional change. Considering different modes of functional mobility illustrates, and thereby helps to elucidate, this point.

Elderly individuals' ability to walk often becomes compromised; accelerating mobility limitation is characteristic of advancing into very old age. Moreover, being unable to mobilize in the usual way disturbs how the physical world seems, as the person is deprived of the usual spatial experience, such as coming closer physically to objects or distancing them, and approaching and even grasping desired things or escaping unpleasant ones.

When their capacity for their former mode of mobilizing declines (from muscle or joint deterioration, stroke, loss of balance or vital capacity, or similar problems of old age), elders too often are confined to wherever caregivers place them, in chairs or beds, thereby constricting their sense of personal freedom to that of a small child in a stroller or crib. And when one cannot mobilize at will, the aspect of well-being associated with personal autonomy may be extinguished. Immobility thus can debilitate an individual's capacity for spatial judgment and perception, causing serious symptoms of disorientation as well. To be disoriented is to lose one's sense of position in relation to physical, temporal, and social surroundings, and to be befuddled in regard to one's identity and direction. This avoidable outcome of biological changes that come with age, and not necessarily those changes themselves, can destabilize health.

So it is not old age itself, nor even the characteristic advent of reduced function in old age, but instead a familiar yet escapable adjunct of such dysfunction that is inimical to health. For, to continue with the illustration, while mobility characteristically becomes compromised in the elderly, being old does not necessitate that disorientation ensue. A wide range of compensatory devices that provide alternative modes of mobilization exist. Users of these devices can approach and withdraw from destinations, thereby preserving their spatial orientation, and can retain their freedom

to choose their own location in space. But often the existing health system plans do not make these available to old people, on the grounds that the elderly cannot be cured, for although these devices restore functionality, users still will not function in the species-typical way. Distressingly, such constraints on health resources, made on the ground that old people cannot retrieve normal health, often needlessly exacerbate the displacement experiences that corrode people's functional resilience, leading to further enfeeblement.

Whether such users are judged irremediably unhealthy and denied health care services because relying on prosthetics and mobility devices to locomote is not considered to be healthy enough, or instead are endorsed as beneficiaries able to achieve through these means the good of health as befits their age, will depend on whether the idea of health is relativized to humans generally or just to humans who have similar long spans of years. If the former, elders cannot help but seem unhealthy as a group, compared with groups of younger people. Moreover, vacillation about social contributions elders should make and concomitant social roles that they might flourish in, adds to the shadows that darken discussions about health and health care for the old. For how can our health care allocation systems assess the prospects for elderly individuals' functionality, and more generally their well-being, if we are not in agreement about what it is appropriate for old people to do?

Conclusion

What a society thinks health is affects not only who receives services, but also which services are received. Medicine (including bioengineering) can provide materials and devices, both organic and inorganic ones, that renew functionality by supplementing or substituting for debilitated or destroyed species-typical modes of biological functioning. But preventing our medical system from begrudging the dispensation of health care to old people calls for biologically sophisticated public discussion, together with a commitment to social justice, to forge more knowledgeable and more inclusive ideas about old age and elder health.

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Ethics, Infertility, and Public Health: Balancing Public Good and Private Choice

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Health care ethicists navigate comfortably in the realm of clinical ethics where the judgment of the individual patient reigns nearly supreme, and the principles of autonomy, beneficence, non-maleficence, and justice are weighed against each other more or less carefully.¹ But they are less sure-footed in the realm of public health, where not the individual person but the whole community is the object of concern, and the main tug-of-war is between the competing values of individual freedom and the public good.² Nevertheless, like it or not, health care ethicists are increasingly being pushed into the public health sector to address issues such as smoking,³ drinking,⁴ and, most recently, eating (obesity).⁵ Moreover, they are being asked to address, as public health concerns, issues that used to be viewed as very private. Among these issues are a host of sexual practices and reproductive choices, including the subject of this article: infertility.

Many causes have come together to put a spotlight on infertility in developing as well as developed countries, but media coverage probably accounts for a goodly portion of the public's interest in infertility in the United States. Who hasn't heard of Octomom, a cash-strapped, single mother of six children, who used fertility drugs to produce enough embryos for eight infants most of whom were born with one or more serious medical conditions⁶; or the sixty-six-year-old Romanian woman in an IVF program who fortunately gave birth to a healthy 3.9 pound daughter, the sole survivor of a triplet pregnancy?⁷ Here, I argue that even if infertility is not, strictly speaking, a disease, it is still a disability that contributes to unhealthiness and often unhappiness. I also argue that a public health focus on infertility makes visible some ethical issues that have been neglected or inadequately addressed at the clinical level. My goal in making these arguments is to

convince public health officials to use health care ethicists more systematically in developing policies for the prevention, detection, and management of infertility that are both socially just and attentive to the value of individual freedom.

I. Health, Disease, and Infertility

Understanding the concepts of health and disease is no easy matter because both of these concepts are variously defined. To begin with, health is not necessarily the absence of disease, disability, or defect because many people with one or more of these "negativities" are quite healthy. For example, although people with the gene(s) for Alzheimer's disease will probably manifest the symptoms of this degenerative neurological condition somewhere down the line, they may be able to lead healthy lives until they are well into their 60s, 70s, or even 80s.⁸ Similarly, people who cannot see or hear, or who have had a limb amputated are often hale and hearty. But if health is other than the mere absence of disease, disability, or defect, then precisely what is health and why should we care about its definition?

Perhaps the most important reason to care about the definition of health—and disease, defect, or disability—is that the definitions of terms affect us in many ways, some of them very significant. For example, if we accept the World Health Organization's (WHO) definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity,"⁹ then most people are somewhat unhealthy. Consider that many individuals experience down-in-the-dumps days that fall short of clinical depression but are nonetheless de-energizing and de-moralizing. Should health care practitioners provide these "unhappy campers" with ample supplies of Prozac or some other antidepressant to boost their low spirits? If so, it would seem that the business of health care practitioners is to make everyone not simply healthy but also happy. After all, it makes just as much sense to define *happiness* as "a state of complete physical, mental, and social well-being" as it does to define *health* with these same words. But, even if the case can be made that physicians should try to make their individual patients happy as well as healthy, public health officials do not always have this luxury. They need to be concerned about the good of society as a whole, a good that may be in opposition to any one individual's happiness and, in some instances, even health, as in a triage situation where not everyone's health care needs can be met.

A. The Natural or Biological View of Disease and Health

Careful reflection on definitions of health—such as the WHO definition of health—puts into focus two competing views of health: namely, the natural or biological view and the normative or socially constructed view.¹⁰ Those who hold the natural or biological view of health assume that all biological organisms, including human beings, are the product of a purposeful and organized biological evolution. They claim that health is best understood as the functioning of a biological organism in conformity with its natural design. On this conception of health, disease is the malfunction of a biological organism. For example, if the lungs are supposed to help human beings breathe, and an individual has emphysema, he is unhealthy.

A variant of the view that disease is some sort of organic malfunction is the notion that disease is a deviation from species-typical functioning.¹¹ So, if most people have a certain blood pressure, cholesterol level, or white blood cell count, then statistically significant departures from the typical condition are probable candidates for the label "disease." Among health care practitioners, physicians seem particularly fond of a statistical view of health, and it is this view of health that

probably accounts for much of the weighing, measuring, and testing that occurs in physicians' offices. Despite the common sense appeal of this view, there is at least one problem with it. Bioethicist Arthur Caplan points out that just because a person deviates from a mean in a statistically significant way does not necessarily indicate that he or she is diseased.¹² For example, Olympic athletes are not viewed as diseased because they can run faster or jump higher than most people. Likewise, people whose IQs (intelligence quotients) or EQs (emotionality quotients) are extraordinarily high are viewed as anything but diseased. Instead, they are viewed as uncommonly blessed people.

A final variant of the natural or biological view of health is offered by physician-bioethicist Leon Kass. For him, "health is a natural standard or norm . . . a state of being that reveals itself in activity as a standard of bodily excellence or fitness, relative to each species and to some extent to individuals, recognizable if not definable, and to some extent attainable."¹³ Confessing that he cannot describe in sufficient detail a healthy human being, Kass instead offers a description of a healthy squirrel—(why a squirrel, I have no clue). Writes Kass:

[The ideally functioning squirrel] is a bushy-tailed fellow who looks and acts like a squirrel; who leaps through the trees with great daring; who gathers, buries, covers but later uncovers and recovers his acorns; who perches out on a limb cracking nuts, sniffing the air for smells of danger, alert, cautious, with his tail beating rhythmically, who chatters and plays and courts and mates, and rears his [sic] young in large improbable-looking homes at the tops of trees; who fights with vigor and forages with cunning; who shows spiritedness, even anger, and more prudence than many human beings.¹⁴

To be sure, squirrels (even super squirrels like this one) are not human beings; and built into Kass's description of the healthy squirrel/human being are several sexist and heterosexist assumptions that detract from its force, to say nothing of the basic assumption upon which it is founded: namely, the belief that there is a natural order that determines the function of each and every thing. Still, Kass's description of a healthy squirrel, with the needed translations into human terms, is not unreasonable for all its flaws.

B. The Socially Constructed View of Health or Disease

Unlike proponents of the natural or biological view of health and disease, proponents of the socially constructed view insist that assertions about values shape the meanings of health and disease. Thus, no matter how many facts we know about the functioning of a particular organ or system of organs, a deviation upward or downward from species-typical or species-average functioning will count as a disease or disability only if people regard the deviation as a disvalue—something to be avoided. Consider the debate that has swirled around homosexuality. Is it a sexual preference, a life-style choice, a sin, or a disease to be treated on account of its statistical deviation from the mean of heterosexuality? Originally classified as a disease by the American Psychiatric Association, homosexuality was declassified as a medical problem by that same group in 1980.¹⁵ Was this change in classification due to some new biological facts that had been discovered about homosexuality—for example, that homosexuals are far more numerous than previously thought, or that most individuals are bisexual? Or, instead, was the American Psychiatric Association's declassification of homosexuality as a medical problem the result of its growing conviction that society should be equally accepting of individuals, whether they have a same-sex sexual preference or an opposite-sex sexual preference?

In the estimation of those who think that the meaning of homosexuality is socially constructed, the answer to such questions is clear: labeling or not labeling homosexuality a disease is a value-based decision, not a fact-based decision.

Another point that bolsters the socially constructed view of health and disease is the fact that what counts as a disease varies from culture to culture. In the United States, epilepsy is a recognized, neurological medical condition that is managed with prescription drugs. In Laos, epilepsy is a sign of spirit possession, something to be left alone for the good of the community.¹⁶ Still, there are limits on viewing health and disease as socially constructed. There are some states of mind and physical conditions that virtually everyone values or disvalues. For example, it is very unlikely that anyone anywhere thinks it is better to have Ebola than not to have it.

II. Infertility as a Devalued Dysfunction (Disease)

Reflecting on how best to understand disease and health—as biological fact or socially constructed value—my own view of disease resonates with Caplan's. He says that disease is a "'disvalued dysfunction' defined in terms of both human goals and the design of the human body (and the human mind, to the extent to which this can be known)."¹⁷ Thus, it is not automatically certain that infertility is a disease or disability. On the one hand, it is a dysfunction, a departure from species-typical functioning. Most couples can get pregnant if they try consistently for a year. On the other hand, infertility may or may not be a *disvalued* dysfunction. Worldwide, the fertility rate has gone down from five to 2.7, and, in the world's developed nations, it has plummeted from five to 1.5, a number lower than the replacement rate required for a stable population size.¹⁸ Japan's replacement rate of 1.3 is very low¹⁹ and other nations with particularly low fertility rates are Russia, Ukraine, Germany, Italy, Poland, Romania, Bulgaria, and Spain.²⁰

To be sure, some of the fertility crisis is the *voluntary* product of people not wanting many children or any children. Specifically, in some European countries, it has been reported that from 12 to 16 percent of women aged 18-34 intend to remain childless, or are inclined in the direction of childlessness.²¹ Still, most of the fertility crisis is *involuntary*. For example, 7.3 million U.S. women aged 15-44 want to get pregnant but experience difficulties conceiving or bringing a pregnancy to term.²² Moreover, upwards of one out of every six heterosexual couples are infertile (that is, unable to conceive during the previous twelve months despite trying).²³ From the vantage point of our species, what is noteworthy about these statistics is that both the number of involuntarily infertile people and the number of voluntarily fertile people are increasing at the same time. Admittedly, it is not as if the world is under-populated,²⁴ but a species that cannot or will not reproduce itself in sufficient quantities is an imperiled species.

In this connection, consider the global implications of increased infertility. The whole emphasis on U.S. aid to developing countries with large populations has been on controlling the size of their populations. Women and men have been offered contraceptives, most of them safe and effective,²⁵ and one of them—the condom for men—with the additional advantage of protecting against HIV/AIDS.²⁶ However, international birth control efforts have not been without controversy. Consider the concerns raised about offering women in rural outposts of Africa the long-lasting contraceptive, Norplant. Pressured by their spouses to have children, some of these women dug the Norplant out of their own arms because they did not have ready access to a medical clinic. Serious infections sometimes resulted from these home surgeries.²⁷ Also consider the furor in India when poor men were incentivized with transistor radios, clothing, and cash to sign up for their free sterilizations. Some

of them had no or little understanding that a vasectomy would end their reproductive capacities.²⁸ Not surprisingly, the one birth control technology that the United States has not offered pregnant women in developing countries is abortion. Because of moral and legal controversies over the status of the unborn fetus in the United States, abortion services have not been provided to women in developing countries. Arguably, much in the way of human health and happiness might have been gained by providing these women with safe abortions. A 2009 study found that approximately 70,000 women died as a result of botched abortions with 38,000 of those deaths occurring in sub-Saharan Africa.²⁹

Although U.S. efforts to help people in developing countries control the size of their populations have not been problem free as just noted, they have been successful enough.³⁰ But what happens when the population size of some developing countries starts decreasing at an unfavorable rate? Will the United States be as eager to provide reproduction-assisting services to these countries as it was to provide them with reproduction-controlling services? These questions are not rhetorical. Recent statistics suggest that infertility in developing countries is a growing problem. The Demographics and Health Survey Program estimates that 167 million ever-married women aged 15-49 years in developing countries (excluding China) were infertile in 2002.³¹ In some developing countries, infertility is three times higher than in developed countries. Among the causes of such high rates of infertility are pelvic infections, botched abortions, and botched deliveries. When there is no one available to perform a Caesarian section, obstetric fistula generally occurs. The United Nations Populations Fund (UNFPA) estimates that worldwide, there may be two million women with this condition. Husbands often abandon wives with fistula, and community support for these women is virtually non-existent. They are treated as lepers.³² Though some of these infertile women may not be involuntarily infertile, most of them are.

Not being able to get pregnant is a prescription for disaster in countries that view women who cannot conceive as useless or defective women³³; and, in such countries, it does not matter if the male member of a heterosexual couple is the one with the infertility problem. The woman will be blamed. Consequently, many infertile women—some of them very poor—are desperate for expensive drugs like Clomid and Pergonal. Moreover, in some countries, including developing countries, the demand for certain infertility treatments, including in-vitro-fertilization (IVF) may not be confined to *infertile* couples. For example, wealthy Chinese couples have come to the United States to undergo both IVF and pre-implantation genetic diagnosis (PGD) in order to secure a male embryo.³⁴ Admittedly, the couples could have used amniocentesis to avoid a female child, but not without subjecting the women to at least one abortion and maybe more. Similarly, where having (biological) children is necessary for maintaining the family line, couples travel far from home to get pregnant. One of the advantages of seeking infertility services abroad is that it is easier to treat male infertility there. The infertile man has less face to lose abroad than in his native country, where “manhood” may be tied to getting one’s wife pregnant.³⁵

To be sure, infertility today is not a public health problem of the same magnitude that over-population was in the 1970s, but it is a growing problem worldwide, and for the one in six heterosexual couples in the United States who cannot get pregnant, it may be a prescription for heartbreak. Ours is a remarkably pronatalist society. The fact that 54 percent of U.S. women work full-time and 11 percent of women work part time in the paid job force³⁶ has not eliminated the socio-cultural norm that motherhood—biological motherhood—is the index

of real womanhood.³⁷ Thus, it is not surprising that more and more people, including infertile people of modest means, are turning to fertility clinics to get pregnant³⁸; and these clinics are feeling increased pressure to “solve” their clients’ problem, even when they feel that they are respecting patient autonomy at the risk of not attending to patients’ best medical interest.

III. Public Health Approaches to Infertility

As I have just pointed out, if clinicians are loathe to say “no” to their patients for fear of thwarting the principle of patient autonomy, perhaps public health agencies like the Centers for Disease Control (CDC), regulatory agencies like the Federal Drug Administration (FDA), and professional organizations like the American Society of Assisted Reproduction (ASRM) and American College of Obstetricians and Gynecologists (ACOG) may help them better balance the values of autonomy and beneficence. These same groups may also remind clinicians that it is better to prevent disease than to treat disease. Among the preventable causes of infertility are tubal infertility which affects 18 percent of the infertile couples in IVF programs. This condition is often the result of chronic pelvic inflammatory disease (PID) which can be prevented by early detection of chlamydia.³⁹ About 1,000,000 cases of chlamydia are reported to the CDC each year. African-American women are about eight times as likely to get chlamydia than white women, and there is increasing evidence that infertility rates are particularly high among poor racial and economic minorities because they have less access to regular health care.⁴⁰

Other causes of infertility are environmental and/or occupational. There are about 84,000 chemicals in the workplace, some of which contribute to infertility, but little research is being done on them.⁴¹ In addition, obesity and smoking contribute to infertility.⁴² Recently, there has been a focus on maintaining the fertility of cancer and HIV patients. Cancer patients need to know that sperm and eggs can be banked, that embryos can be frozen, and that the ovary can be relocated from the field of operation. HIV patients need to know that some of the drugs that promise to save them from an early death may render them infertile, and that if they intend to reproduce they had best bank their gametes before beginning a drug regimen.⁴³ Men and women also need to know they can freeze their gametes for possible posthumous use.⁴⁴

Another way for public health groups to limit the harms associated with infertility treatments is to make sure that the public understands that not all clinics are equally successful in delivering a baby to infertile persons. Although a 1992 federal law required ART clinics to report success and failure rates to the CDC, implementation was slow, and studies continue to indicate that patients are often unaware of how low success rates actually are at some reporting clinics.⁴⁵ In 2009, the CDC found that 441 reporting clinics performed 146,244 IVF cycles in order to produce 45,870 infants.⁴⁶ These statistics suggest that many IVF users are undergoing taxing infertility treatments and spending thousands of dollars only to be disappointed.

One of the main contributions public health groups can make to the oversight of the IVF enterprise is continuing to monitor the occurrence of multiples and setting up guidelines to limit their occurrence. Insufficient oversight of the IVF enterprise is unfortunate because of the role physicians in particular play in the reproductive drama. Judy E. Stern et al. comment that:

Risk to the patient is of particular concern when treatment is elective because in such cases the patient would be healthy but for the medical intervention. Risk to the offspring in treatment of infertility is particularly significant in light of the fact that the offspring would not exist and thus would not suffer but for the medical

intervention. This unique aspect of the treatment of infertility may impose a higher standard on physicians considering potential risks to these offspring.⁴⁷

Although many physicians do hold themselves up to such higher standards, some do not. They may find it difficult to say “no” to patients. They may also fear their patients will just take their business to some other, more accommodating fertility clinic. As late as 1995, the Institute for Science, Law, and Technology (ISLAT) collected data from 281 reporting clinics some of which were still implanting as many as seven embryos during one IVF cycle. At that time, 37 percent of ART births were multiples as compared with 2 percent in the general population.⁴⁸ More recently, the CDC has reported that 32 percent of ART births are multiples as compared with 3 percent in the general population.⁴⁹ All multiple births, even those of twins, pose serious health risks for both the mother and the infants; the human uterus is not designed to carry multiples. Therefore, it may be prudent for the CDC to exert even more leadership and press for single embryo transfer (SET) for women under the age of 35 as the gold standard for ART clinics. It would be the clinic’s responsibility to explain why deviations from this standard were necessary.

Another issue, and a controversial one at that, is for the CDC to educate women in particular about their “biological clocks.” In the early 2000s some scientific studies were published stating that the best time for women to have children was between the ages of 20 and 35,⁵⁰ and that women who waited too long to become mothers risked infertility and possibly the disappointment of not being able to be biological mothers, technology notwithstanding. A number of women’s groups reacted angrily to these studies, viewing them as scare tactics that might lure women out of the marketplace and back into the household.⁵¹ The controversy was not resolved, but simply temporarily “solved” by the new option of egg freezing.

Recently, my mid-twenties graduate student went to her obstetrician-gynecologist. When the physician found out that my student was going to law school, she immediately asked her if she had considered freezing her eggs so as to be able to postpone pregnancy until her 30s or 40s. Promoting the egg-freezing option may or may not be the way to go for all women, however. After all, the total costs of egg freezing and IVF are considerable,⁵² and the older a woman is, the harder the pregnancy experience may be.⁵³ Moreover, the chances of a live birth from IVF using frozen eggs is 1-10 percent compared to 17 percent with IVF using fresh eggs.⁵⁴ Clearly, there are many reasons for people to engage in informed discussions about “the biological clock.”

Yet another issue to more aggressively address is the lack of insurance coverage for costly treatments such as IVF. In 2004, only the following states mandated infertility insurance coverage: Arkansas, California, Connecticut, Hawaii, Illinois, Maryland, Massachusetts, Montana, New York, New Jersey, Ohio, Rhode Island, Texas, and West Virginia; and most of these states’ coverage for IVF was very limited.⁵⁵ And although Medicaid covers treatment for sexually transmitted diseases, it does not cover infertility treatments like IVF.⁵⁶ In fact, were it to cover IVF, the public would probably express outrage, as it did in the 1970s when someone interpreted Medicaid rules to provide women on welfare with coverage for insemination with donor sperm.⁵⁷

But possible public outrage should not distract anyone interested in narrowing health care disparities and health status disparities. If infertility is a disease or disability, as I think it is, treatment for it should be provided. Left untreated, infertility can contribute to much psychological anguish, especially for those people who refuse to consider adoption

or a childless life as a good option for themselves. The fact that only some states mandate infertility insurance coverage, and in limited ways at that, means that most people, including people without health care insurance, pay out-of-pocket for infertility services. Thus, only wealthy infertile people can absorb the costs of IVF—about \$12,000 per cycle—without significantly affecting their financial well-being. To be sure, infertile people of more modest means can and do use a full array of infertility treatments, but they often go into heavy debt in the process of trying to have a baby⁵⁸; and people without any financial resources whatsoever know full well that no fertility clinic will welcome them with open arms. Narrowing the health care gap between wealthy women and infertility insurance-covered women on the one hand and poor women and women without any kind of insurance on the other hand is important for anyone who advocates social justice and believes that infertility is a disease or disability.

Conclusion

Bioethicist Leon Kass has made many distinctions between health and happiness, not all of them popular. Still there is wisdom in many of his views. He claims, for example, that acts like removing a normal breast because it interferes with a woman’s golf swing or performing amniocentesis and then aborting the fetus if it is the “wrong” sex are:

acts not of medicine but of indulgence or gratification in that they aim at pleasure or convenience or at the satisfaction of some other desire, and not at health. Now, some indulgences may be necessary in the service of healing, as a useful means to the proper end: I see nothing wrong in sweetening bad tasting medicine. But to serve the desires of patients as consumers should be the tasks of agents rather than doctors, if it should be the task of anyone.⁵⁹

Interestingly, some fertility specialists admit that they are more in the happiness business than the health business. When critics questioned Dr. Silber for transplanting an ovary from one sister into her sibling, some of his defenders stated that the surgery was just like any other organ donation. However, one of his defenders candidly admitted that the primary goal of an ovary transplant is making a woman happy and not necessarily healthy. Commented Dr. Richard Gimpelson: “These other organs are donated to save someone’s life. The ovaries are to make someone’s life complete. It’s a little bit different.”⁶⁰ Actually, ovary transplant may be a lot different. Little is known about its health risk and benefits and yet this surgery is already being promoted to women as an option they should consider.

When infertility practitioners push the envelope of infertility treatments, there is a role for regulatory agencies to play. When medical treatment turns into unmonitored medical research, the public’s health is at risk. Rather than encouraging women to view egg freezing and IVF as their treatments of choice, infertility practitioners should first spend time fighting the causes of infertility, even if doing so means a downtick in their lucrative practice. The CDC is correct to emphasize how untreated sexually transmitted diseases may make women infertile. Treatment for such diseases should be very inexpensive, if not free, so as to decrease the health status gap between women who have good health care insurance and women who have no or inadequate health care insurance. In addition, the CDC should play a stronger role than it already does in researching the cost-effectiveness of IVF versus other, less high-tech options for treating infertility and reporting the availability of insurance coverage for infertility treatments. Factors such as these last two also contribute to the health

care and health status disparities that exist in the United States. Finally, the regulatory agencies all need to demand greater accountability from fertility clinics with respect to multifetal pregnancies. Twins, triplets, quadruplets, and higher-numbered multiples seem very cute on popular magazines covers, but for every one of these adorable photos, there are thousands of multiples in intensive care units who may always suffer from one or another health condition because they were born too early or at an extremely low weight.

Infertility is indeed a public health concern that we all must address. Health care ethicists need to be included in the discussion loop more routinely so as to help strike a better balance between the values of individual freedom and the common good. Creating a life remains one of the most important hopes of human beings; and the more we can do to preserve the fertility of people, the better our collective as well as individual health and happiness.

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Disability and Disadvantage through the Lens of Value Theory¹

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A Radical Thesis

According to some disability advocates, so-called disabilities are really just differences in functioning from those considered normal.² Such “disabilities” as blindness, deafness, dyslexia, and paraplegia are not *inherently* disadvantageous any more than being non-Caucasian is inherently disadvantageous. Disadvantages are due, in large measure, to discrimination and lack of consideration on the part of the “abled” majority. Thus, any disadvantages are contingent. They are not a necessary consequence of an objectively bad condition.

Whether a given condition is perceived as a disability, the argument elaborates, depends on the environment, context,

and existing social arrangements. Unless one wants to be a pilot, color-blindness generally goes unnoticed by others and is not considered a disability. But if traffic lights placed green and red lights in different configurations so that colorblind people could not distinguish them by position, their ability to drive safely would be greatly impaired and they might be regarded as disabled. Dyslexia is considered a significant disability only where reading is expected. Before reading was part of human culture, the same physical condition was probably not noticed, much less considered a handicap. Deafness is considered a disability by a hearing majority that uses spoken language and telephones. But deafness is really just a difference—one that need not pose disadvantages in certain environments. If everyone signed rather than spoke, and texted rather than called by telephone, the hearing majority might not consider deafness a disability. Indeed, if our world were filled with loud, varying noises that consistently distracted hearing persons, hearing might count as a disability.³ Disabilities, the argument concludes, are just differences.

This argument provokes the question of whether disabilities are inherently disadvantageous. Addressing this question requires an excursion into prudential value theory. I argue that a well-navigated excursion leads us to reject the claim that disabilities are mere differences, but also to accept far more of what disability advocates often claim about their quality of life than the “abled” majority commonly accepts.

Value Theories and their Relevance to Disabilities

Prudential value theory (“value theory” for short) features competing accounts concerning what, at the most basic level, constitutes individual well-being or flourishing. Such an account offers a view about what counts as a benefit, what counts as harm, and what makes an individual’s life go better or worse from the standpoint of her own interests.

Value theories can be grouped, at a general level, into subjective accounts and more objective accounts. Subjective accounts understand our well-being to be ultimately a function of our having certain valuable mental states and avoiding contrary mental states. Classical hedonists, for example, argued that well-being is happiness, where the latter was equated with pleasure (in all its many varieties) and the absence of pain (in all its varieties).⁴ Responding to the point that we value things in addition to pleasurable or agreeable mental states, an alternative subjective approach construed our well-being in terms of the satisfaction of our desires or preferences—the objects of which could include not only agreeable feelings, but also states of the world such as achieving something or having friends.⁵ Because we sometimes desire things that do not prove conducive to our welfare, some theorists refined this approach so that our well-being was a function of the satisfaction of those desires we would have *if adequately informed*. But this theory, too, proved problematic. For one thing, we might have an informed desire for something, such as being promoted—and then find, when this desire is satisfied (when we get what we wanted), that *we* are not. If satisfying an informed desire produces no *felt* satisfaction, it is unclear why it should count as valuable on a subjective account. Moreover, an informed desire might be satisfied—what you want happens—without your being aware of it; indeed, you might be dead when it happens. There is arguably something odd about a theory that suggests that you benefit from such remotely satisfied desires. Thus, one might doubt that it is the satisfaction of desires *per se* that conduces to well-being.

Among those who are skeptical about the prospects for desire-satisfaction theories, some defend more objective accounts of human well-being. I say “*more* objective” because it is widely appreciated today that any plausible account will

have to have some subjective elements—allowing, for example, that enjoyment generally promotes well-being, and making room for individual differences in temperament, taste, and nature in determining what makes a particular individual well-off. These accounts are significantly objective in maintaining that certain human activities, forms of functioning, or states of affairs are intrinsically valuable for one—irrespective of the pleasure, enjoyment, or satisfaction they bring a given individual, and whether or not he prefers them. For example, it is sometimes argued that one is better off, other things being equal, if one has deep personal relationships, accomplishes something, achieves understanding of important matters, lives autonomously, and experiences enjoyments.⁶ A recent trend has been to characterize these and other allegedly objective components of human well-being in terms of *capabilities* to function in various ways: physically, mentally, and socially.⁷ In an effort to show that their approach is not implausibly remote from human experience, theorists of this stripe maintain that objectively valuable components of human well-being are such that people *characteristically* desire them and find them satisfying—even if there are exceptions.

Subjective accounts of well-being clear more conceptual space than do objective accounts for the thesis that disabilities are mere differences. On subjective accounts, a given disability need not be disadvantageous for a particular individual even if it disadvantages most people who have it. Perhaps it is true that blind people experience more frustration and suffering, on average, than sighted people, for reasons connected with their blindness. But if a given blind person is just as happy (however this concept is defined) as the average sighted person—and just as happy as he was before becoming blind (if the impairment was acquired)—there is no basis for judging his well-being to be lower just on account of blindness. If it doesn't make him less happy, it doesn't make him worse off, according to the subjective theorist. Moreover, the fact (if it is a fact) that blind—or deaf or paraplegic—people tend to be less happy than their “abled” counterparts has plenty to do with social arrangements, institutions, and attitudes that could be improved. So, even if some group of disabled people is less well-off *now*, that is likely to be a contingent fact rather than a necessary consequence of their disability, according to the subjectivist theorist.

By contrast, an objective theorist—especially one who emphasizes functioning or capabilities—is likely to judge major disabilities as *per se* injurious to well-being. To be unable to see is to be unable to function in an important way that is not only instrumentally valuable—helpful for many things we want or need to do—but also intrinsically valuable. To be unable to walk is not only enormously inconvenient; it is also the deprivation of an intrinsically valuable activity.

What should we make of people who have significant disabilities yet sincerely deny any frustration with them? In such cases, the objective theorist asserts, we must take into account the phenomena of *self-deception* and *adaptation*, which can distort a disabled (or otherwise disadvantaged) person's self-assessments of well-being. We deceive ourselves when we permit ourselves to believe something we would like to believe despite strong evidence to the contrary. A disabled person may talk herself into the belief that she is faring just as well as she would without the disability, but this self-assessment is unreliable. In cases where individuals *lose* functioning as a result of illness or accident, adaptation is common: After an initial period of frustration and felt loss, the individual adapts to his new circumstances and, in time, reports increasing satisfaction with his life, sometimes to the point of feeling as well as he did prior to the loss of functioning. These cases may involve self-deception. Very commonly they involve a *lowering*

of expectations such that one comes to have desires (e.g., to get outside in any way possible) that are easier to satisfy than earlier desires (e.g., to run vigorously). In an analogous way, a stoical prisoner may shed old desires for liberty and take solace in modest victories such as getting a decent sleep or not being harassed all week. But, even if he feels as satisfied with his new lot as he was with his old, he is, according to the objective theorist, worse off for being confined. Thus, one of the most significant challenges to subjective theories, and the view that disabilities are mere differences, is the intuitively powerful claim that certain activities such as seeing, hearing, and taking a walk are objectively, intrinsically valuable. This claim implies that disabilities that preclude such activities necessarily, to some extent, diminish well-being.

Defense of a Subjective Value Theory

Against current trends in the value theory literature, I submit that the best possible subjective theory is more plausible than any objective theory. To motivate this claim, consider the rather bold assertions to which an objective theory is committed. Note, first, its tendency to second-guess the positive self-assessments that are often advanced by disabled persons. Of course, there is such a thing as self-deception, which can distort one's optimistic reports, but we should attribute self-deception very cautiously. Moreover, why should adaptation be considered an evaluative distortion? Yes, the satisfaction of modest desires tamped down by a loss of functioning—or any major setback—may be less of an achievement than the satisfaction of more ambitious desires, but this judgment of comparative achievement might not be relevant to the issue of *how well the subject's life is going for her*. Reassessing one's aims and making them more modest might be the wisest course in the face of loss or misfortune; and it is not obvious that one's new, lower baseline of expectation is necessarily a distorted baseline for determining well-being. I suggest that, if the blind person *really is* just as happy or satisfied as the sighted person, or if the prisoner really is as happy now as she was prior to imprisonment, there may be no reason to judge that in each case the former is less well-off than the latter.

In addition to being presumptuous in second-guessing stoical individuals' self-reports, the objective approach is theoretically presumptuous. Or, at any rate, it carries a heavy burden of justification. For objective theories assert the existence of standards of well-being that are to apply to individuals irrespective of whether those individuals care about the standards or resonate experientially with them. For example, an unambitious person who seems perfectly happy with his life is judged to be less well-off for lack of accomplishment—even though he doesn't desire accomplishment and correctly believes that it wouldn't make him happier. It's no doubt true that most people find accomplishment satisfying. But, for one who doesn't, it is unclear that his life, lacking accomplishment, is less good *for him*. I do not claim that the objectivist's assertion is unintelligible or conceptually incoherent. Rather, I claim that it is a bit odd and stands in need of a strong justification—which, in my opinion, no one has supplied. By contrast, the fact that something such as accomplishment or friendship makes a given person happier and more satisfied certainly seems to be evidence that it makes her better off, consistent with subjective accounts.

One motivation for objective accounts is the perception that subjective accounts have insuperable difficulties. Here I will identify and reply to what I believe to be the three most significant challenges. First is the challenge to define happiness in some way that is more plausible than the usual reduction to either pleasurable feelings or desire-satisfaction. The second major challenge is to avoid a seemingly absurd implication of

subjectivism: that a person who is happy only because all of her beliefs are systematically and profoundly distorted is well-off.⁸ The third major challenge is to respond adequately to the point that adaptation to hard circumstances—such as a substantial acquired disability or a socioeconomic or political setback—can involve lowering one’s expectations, with distorting effects on self-assessment of well-being. A slave, accustomed to a life of profound subordination, may have very modest expectations that are satisfied, and may feel satisfied, but such satisfaction obscures the assault on well-being that slavery entails.

In response to these challenges, I briefly offer three suggestions. The first is to define happiness not in terms of agreeable sensations or desire-satisfaction, but as *life-satisfaction*: satisfaction with how one’s life as a whole is going for one in terms of one’s own priorities (where such satisfaction includes both the belief that one’s life is going well and feeling good about it).⁹ The second suggestion is to include a *reality-based* requirement for well-being. One’s happiness makes one well-off only if it is based on a more or less accurate understanding of one’s circumstances. With this requirement, a person whose happiness rests on thorough-going delusion is not well-off. The third suggestion is to accept the victory of stoicism. So long as a person’s adaptation (e.g., to political imprisonment or slavery) is accompanied by a realistic appraisal of her circumstances, we should accept her sincere reports of her own well-being.

Implications for Disability and Disadvantage

With this theoretical discussion in hand, let us return to the question of whether disabilities are inherently disadvantageous. If I have been right to endorse a subjective theory of well-being over any objective approach, then it follows that—in one important sense—disabilities need not be disadvantageous. A person can be disabled and fare just as well as a person who occupies identical circumstances except for lacking the disability; the disability *per se* does not count negatively in assessing his well-being. It doesn’t follow, however, that disabilities are mere differences.

Disabilities involve the absence of a kind of functioning that plays a significant role in human life. To be blind, for example, is to “begin” with a disadvantage. Being able to see is a massive advantage. Sighted people treasure the ability to represent the world visually and presumably find some intrinsic value in visual experience. Now, someone who has *never had* vision may not lose out, in terms of intrinsically valued experiences, from not seeing—just as sighted people don’t lose out from not seeing ultraviolet light and not experiencing bat-like sonar.¹⁰ But the *instrumental* value of vision to human beings across the board, in the world as we know it, is enormous, and this fact has an irreducibly biological (as opposed to social) basis: Animals evolved vision because it is so helpful for navigating. To be sure, through adaptation, self-discipline, and the like, a blind person may manage to be just as well off as a typical sighted person—but to do so is to beat the odds and overcome the instrumental disadvantage. So we might say that disabilities are (1) *presumptively* disadvantageous in the sense of presenting an obstacle (even when social accommodations are abundant), but (2) *not necessarily* disadvantageous in that some persons with disabilities, despite their obstacles, fare as well as their “abled” counterparts or, in the case of acquired disability, as well as they themselves fared prior to becoming impaired. Importantly, these persons with disabilities are not less well-off than their level of (informed) happiness suggests.

Because disabilities are *presumptively* disadvantageous, it must be considered harmful and *pro tanto* wrong to cause someone to have a disability.¹¹ Typically, disabilities reduce opportunities and create burdens for those who bear them,

causing frustration and reducing satisfaction. This suggests what is valuable in objective accounts, for they identify conditions, types of function, and states of affairs that—generally speaking in the world as we know it and with human beings as we know them—tend to make life go well. Objective theorists are right that close personal relationships, accomplishment, living autonomously, and certain forms of physical and mental functioning generally make a human life go better. Their error is to overgeneralize by claiming that these conditions and forms of functioning are such that their absence *necessarily* diminishes human well-being. If my assessment is correct, then the value of objective accounts is that they provide a presumptive list of welfare-conducive conditions—which our social policies and parental decisions should generally support. Meanwhile, the strongest possible subjective value theory, I have suggested, does not overgeneralize in attempting to capture the ultimate constituents of human well-being, including the well-being of persons with disabilities.

Endnotes

1. This paper was presented at the American Society for Bioethics and Humanities annual meeting in Minneapolis on October 14, 2011. I thank attendees for their thoughtful feedback. The ideas for the paper were drawn from a section, “The Thesis that Disabilities are Really Just Differences,” in *Creation Ethics: Reproduction, Genetics, and Quality of Life* (New York: Oxford University Press, forthcoming 2012).
2. See, e.g., Union of the Physically Impaired Against Segregation, *Fundamental Principles of Disability* (London: UPIAS, 1976) and Ron Amundson, “Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics,” in *Quality of Life and Human Difference*, edited by David Wasserman et al. (Cambridge: Cambridge University Press, 2005), 101-24.
3. I have heard David Wasserman advance this good point.
4. See, especially, Jeremy Bentham, *An Introduction to the Principles of Morals and Legislation* (1789).
5. See, e.g., A. J. Ayer, “The Principle of Utility,” in *Philosophical Essays* (London: Macmillan, 1954), 250-70.
6. See, especially, James Griffin, *Well-Being* (Oxford: Clarendon, 1986).
7. See, e.g., Martha Nussbaum, *Women and Human Development* (Cambridge: Cambridge University Press, 2000).
8. For a classic discussion, see Robert Nozick, *Anarchy, State and Utopia* (New York: Basic, 1974), 42-45.
9. This suggestion and the next come from L. W. Sumner, *Welfare, Happiness, and Ethics* (Oxford: Clarendon, 1996). With the third suggestion, I part ways with Sumner’s account.
10. David Wasserman makes roughly the same point (“Philosophical Issues in the Definition and Social Response to Disability,” in *Handbook of Disability Studies*, edited by Gary Albrecht et al. [London: Sage, 2001], 232-33).
11. Matters become enormously complex when “causing” someone to have a disability involves bringing someone into existence where it is predictable that he or she would have the disability, yet could not have existed without it. I address such reproductive choices in *Creation Ethics*, Chapters 5 and 6.

Enhancing Persons, Commodifying Bodies¹

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In the acknowledgement section of his little book, *The Case Against Perfection* (Harvard, 2007), Michael Sandel writes that he appreciates that the Carnegie Corporation allowed him to take “an intellectual detour along the way to a future (and not wholly unrelated) project on the moral limits of markets.”² It’s

the parenthetical phrase that captured my attention, and it serves as the point of departure for this talk.

For in that book, Sandel tries to articulate, and defend as fully rational, a sense of unease prompted in many people by the prospect of using biotechnologies to enhance human capacities. For my purposes here—and I think Sandel's as well—what is most in need of articulation and defense is that unease emerges from less commonly explored regions of our moral sensibilities. That is, he's not particularly interested in situating various proposed enhancement regimes against deontic notions (rights, respect for persons, autonomy, justice), nor is he chiefly concerned to speculate about the balance of utility and disutility that might ensue from the dissemination of biotech-mediated enhancements (at least not if we accept that "utilities" mean something not already moralized—e.g., "interest satisfaction" as opposed to moral excellence). Rather, he's troubled by what might be called, not altogether happily perhaps, the expressive impact of enhancement. The fear is that such practices may reduce our ability to acknowledge or convey, to ourselves or to others, our sense of the value of certain important features of human life.

As will emerge, I don't find Sandel's worries here particularly compelling. However, what I do find troublesome might be called the expressive impact of certain modes of commodification and, in particular, the commodification of human organs to increase transplantation opportunities. And this provides me with my present problem: If Sandel's worries can be set aside, as I propose to do here, why couldn't a similar argument convince me that my concerns about the "not altogether unrelated" moral limits of markets are equally ill-founded?

As I read him, Sandel's most concerned that to the extent that we succumb to the temptation to develop and deploy enhancement techniques, we will be attenuating—gutting, really—our ability to appreciate of the dimension of "giftedness" in human life. With giftedness gutted, our humility will flag, we'll develop an overweening sense of our own powers of achievement, and it will become progressively more difficult for us to nourish the moral sentiments that underlie our sense of solidarity with one another (Sandel 2007, 85-92).

At least some commentators have been pretty rough with Sandel's "giftedness" move. Alan Buchanan in particular has given him a hard time about it, offering characteristic powerful and unsparing arguments in support of seeing Sandel's book as an essay in *a priori* sociology and psychology. We can almost feel the breeze as Buchanan shakes his head and intones, "One would think that one was living in the eighteenth century, when serious intellectuals still believed they could formulate interesting and controversial generalizations about human behavior or the workings of human society from the armchair."³

I'm not inclined to be so censorious. There is something in the neighborhood of *a priori* connection among the contents of our attitudes, and I allow that if one saw everything about life as a result of achievement—the triumph of the will in spades—there wouldn't be much room remaining for any robust sentiment of humility, nor, possibly, of solidarity, at least if not everyone's will was so triumphant. Could one really assert "Everything of any value in my life is a function of my own unaided strivings and success, but all the same, I'm humble in the face of my own achievements"? While I don't see a formal contradiction here, I do think that we'd wonder whether a person who, innocent of irony, asserted such a claim, really grasped what "humility" means. The problem here is a matter of what Wittgenstein might have called "grammar," and not of contingent experiential links that need social scientific support. While Buchanan is right, of course, that the social impact of

these attenuated attitudes would be a matter of fact, I think Sandel does not deserve quite the scolding he gets for thinking that we'd have reason to be concerned.

My problem is not that Sandel is mistaken about a connection between the loss of a sense of giftedness and prospects of experiencing and conveying humility and solidarity. The problem is with the notion that enhancements—even the biotechnical kind—must eviscerate our ability to appreciate and otherwise express a sense of giftedness in the first place. The notion that the development and deployment of any of the range of enhancements that are in any sense practical politics would make it no longer the case that human life includes conspicuous amounts of what is merely given, of what the Greeks called *tuche* and we "luck," seems fantastic to me, and I must think, to Sandel as well. The charitable interpretation is that something about how those interventions would be understood would make unavailable to us the thought that our lives, actions, passions, and capacities are fragile and limited and not altogether of our own fashioning, and thus deplete the resources we use to make sense of the sentiments he wants us to wield.

Yet even the charitable interpretation doesn't do all that much for Sandel. What needs to happen here is a little sober *reframing* of the issue and some timely reminders: the fundamental physical structure of the universe is not a function of our wills; accident and tragedy will abound even if some few of them are eliminated or reduced by biotechnology; the concatenation of events that have to come together in a "unique endeavor" to bring forth what Larkin called "the million-petaled flower of being here" continue to have been incredibly unlikely for all of us, and nothing for which we deserve any credit.⁴ The very desires, drives, and abilities that make biotechnical enhancements so much as possible *precede* our actions, rather than resulting from them. And so forth, and so on.

But now I come to the problem I flagged earlier, which is not with Sandel, but with myself. For although I am not persuaded of the seriousness of "expressive" style arguments against biotechnically enabled human enhancement, I am inclined to want to limit markets, and some of my reasons for wanting to do so have an expressivist character to them. I think that withholding some items from the market is a way to convey and maintain our recognition of the distinctive forms of value that those items have and that our various kinds of engagement with them can convey. The worry is this: to buy or sell people, or their babies, or their organs, is to regard all such things as items for whatever kind of use they can be put to, and to see their value as commensurate with anything else that could be given a price and placed on the market. But use is not the appropriate mode of valuation for everything, and not for these kinds of things in particular. Some things are not for use but for appreciation, or respect, and these modes of assessment rest uneasily with the commensurability implicit in market transactions, and in particular with the notion of ownership that such transactions, purely understood, are taken to license.⁵

There's obviously lots to be said, one way and another, about this. But my worry here is whether my argument against Sandel's use of expressivist concerns couldn't be turned against me. I claim, in effect, that meanings are not tied down to practices so tightly as Sandel thinks, that nothing compels us to regard a technologically enhanced form of human life as though it were devoid of the given and the gifted. It surely is not, and if the glitter of technology inclines anyone to think otherwise, the means for their correction are quite plainly at hand. If, however, such considerations undermine Sandel, why could they not be applied to expressive-style arguments against a market in organs, or babies, or people generally?

If there's an important disanalogy between Sandel's anti-enhancement position, and the anti-commodification line I'm roughing out, I think it must be provided by the institution of the market, which serves as the context for commercial transactions and is constituted by practices that confer and express a certain kind of value. The closest parallel to the market in the enhancement case—that is, the semantic backdrop that strongly influences the relevant meanings of the relevant practices—seems to be the notion of giftedness. Giftedness in turn seems to be constituted by a broadly “pro-attitude” (ranging somewhere from grateful acceptance to awe-struck wonder) prompted by features of reality that (as a necessary, not sufficient condition) are not altogether our doing.

It's a bit of an inverted parallel perhaps—the expressivist objection to enhancement rests on its making the notion of giftedness, and its related moral sensibilities less available to us, whereas the corresponding objection to commodification rests on the market's imposing its limited currency of evaluation more broadly than it ought. That difference, however, shouldn't matter. What might matter are the different ranges of interpretation that are available in either case. In Sandel's case, the worry is that biotechnical enhancements will decrease our appreciation of giftedness, with all the problems attending thereunto. My reply is that there is no need for it to do so at all; if anyone responds like that, it would seem perfectly appropriate to tell them that they needed to get a grip and take a good look around them.

In my case, the worry is that commodification of some items will erode the resources we need to draw on for the distinctive kinds of valuation they merit—that, to take an easy example, if we accept that human infants merit dignity rather than price, it isn't open to us to auction them off to the highest bidder, all the while saying that we simultaneously respect their dignity—“Good heavens, yes, we're just *full* of respect for that”—as we bang the hammer down.

One could, of course, *stipulate* that respecting something in the way of dignity is compatible with pricing that item—but that, of course, is not an argument. Or, one might argue that dignity as we do in fact understand it is compatible with price, and that Kant was just wrong. But while that would be an argument, all right, it would require an account of just what kinds of restrictions on the use of that item one commits oneself to in claiming to respect it. In contrast, it is a mere observation that even “transhumans” would live against a backdrop of a world that would remain largely independent of their wills. They are deprived of nothing they need to feel humble when they gaze at the starry heavens above and consider the moral law within.

The hard example, of course, is human organs. Even if *some* items—persons, paradigmatically, and some of what they do (e.g., exercise their franchise or their sexuality)—merit kinds of evaluative attitude that are incompatible with commodification, why should such attitudes seem mandatory for items that are merely (replaceable) parts of human bodies? I can here do no more than gesture in the direction of a partial answer: cadaveric transplantable organs are not items that it would be legitimate to withhold from those in great need *on the grounds that one didn't like the price one was being offered*. Which is to say, that they cannot be rightly understood altogether as though they were commodities. But, as the tell-tale compression of the pages indicate, motivating this view, and drawing out its implications, is a task for another day.

Endnotes

1. Presented at the ASBH Annual Meeting, October 13, 2011. Thanks, as always, to Professor Hilde Lindemann for her close reading. I'm also grateful to the participants in the session, particularly to Dr. Joseph Millum, who underlined that some

items that are valued otherwise than as commodities—e.g., pets—are bought and sold. While pets are, perhaps, beings for whom some non-market modes of valuation are seen as optional (thus distinguishing them from, e.g., children) Millum's observation underscores a point that Anderson (1995) also makes: commodification can be a partial phenomenon. The argument here cuts most effectively against “full” commodification, and therefore its relevance against some current proposals to provide financial incentives for organ provision (such as defraying funeral costs) are less clear.

2. Sandel, 2007, p. ix. The book on markets to which he refers—*What Money Can't Buy: The Moral Limits of Markets*—is now available.
3. In his *Beyond Humanity?* (Oxford: Oxford University Press, 2011), 9.
4. Philip Larkin, “The Old Fools,” *High Windows* (London, U.K.: Farber and Farber, 1974).
5. Many have advanced arguments of this general sort. I'm most influenced by Elizabeth Anderson's discussions in her *Values in Ethics and Economics* (Cambridge, MA: Harvard University Press, 1995).

Like a Cigarette Should

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“My cancer has improved my life,
As now I savor every minute
And better love my child, my wife,
The world, and all the beauty in it.”

If that is how you truly feel
(You hardly sound as though you're joking),
Then why not launch a mass appeal
And urge us all to take up smoking?

Is Choice Good or Bad for Justice in Health Care?

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Patient autonomy in choosing treatments has become one of the basic principles of health care ethics. Of course, it is not the only value and debates continue over how conflicts between autonomy and beneficence can be resolved. The dilemmas over the value of patient autonomy are familiar topics in medical ethics. Although informed consent by competent patients is a standard requirement for treatment so that the fact that the treatment is beneficial or medically indicated is not sufficient to make treatment ethical, questions arise as to whether there is a limit to the patient's right to choose. Can the patient refuse treatment that is needed to keep him alive? Should the patient be allowed to choose in a way that harms other people, for instance her family? Can the patient demand treatment that the physician considers medically futile? How far can the patient's autonomy be extended through advance directives? Should the patient's request for assisted suicide or euthanasia be granted?

In this paper, I examine the conflicts between autonomy and another ethical principle: *justice*. The problem of justice in health care concerns both micro-allocation and macro-allocation. The latter has to do with distributive justice: who should get what health care resources at whose expense. The current debate about health care reform brings up two competing models of distributive justice from political philosophy. The libertarian theory holds to the ideal of individual responsibility and choice, viewing taxation for the purpose of providing goods to those who cannot afford them as a form of unjustified coercion. The liberal theory holds that society should ensure that all members are provided with basic goods that correct for inequalities that deprive them of human dignity. Even though both theories value individual choice, these theories provide opposing answers to the question of whether taxes should be collected and used for the purpose of ensuring universal access to health care.

In this paper, I show that neither theory can respect patient choice in health care and achieve distributive justice. Libertarians ignore the realities of the health care system and why a free market where patients choose and pay for what they want cannot exist. Liberals on the other hand face the problem that the choices that patients make can lead to over-consumption of health care at the expense of other goods important to society. I consider some limitations on patient choice needed to achieve justice in allocating health care resources by examining health care reform taking place in the United States.

I

The Council on Ethical and Judicial Affairs of the American Medical Association has issued a document on *Fundamental Elements of the Patient-Physician Relationship* that includes the following clause:

6. The patient has a basic right to have available adequate health care. Physicians, along with the rest of society, should continue to work toward this goal. Fulfillment of this right is dependent on society providing resources so that *no patient is deprived of necessary care because of an ability to pay for the care.*¹

Needless to say, this right has not been fulfilled in its entirety at any stage in the history of health care in America or any other country. The reasons for this are quite apparent. Health care is costly and a large number of patients are unable to pay for what they need, especially towards the end of life. Advances in technology have multiplied the cost and range of available means to keep patients alive. One may argue that extraordinary means are not necessary means. Could a minimum decent standard of health care be guaranteed to every citizen? A very low standard makes it more likely that every citizen can obtain health care, but since there are unemployed and homeless people who are struggling to find the means to feed and shelter themselves, there will always be people who cannot afford to pay for health care even at a basic level. But if the minimum standard is set too low, would most people be denied less basic health care that could benefit them? If the minimum decent standard includes more than the bare minimum, how is that going to be provided by society?

The AMA statement does not elaborate on how society is to provide resources for health care and what the basic right to health care amounts to. So it is compatible with a system where everyone has to pay for their own health care, except for the indigent who gets free care in emergencies. It is also compatible with a system where the state provides a lot more than basic health care to every citizen, up to the limit of what the state has resources to pay for. These are two extremes reflected in the

libertarian and liberal theories of distributive justice. Before I discuss these theories, I shall look at how much room there is for patient choice in these systems.

As debates about autonomy in medical ethics have shown, the definition of autonomy is itself problematic. There is a sense in which either system could be said to protect patient choice. One could argue that choice is about not being prevented from getting what one wants and can afford to get. The limited options that one has and the non-availability of an option is not a deprivation of autonomy. So getting what you pay for is what choice is about. An obvious criticism of this idea of autonomy is that something being unaffordable is one way of being prevented from getting what one wants. As for the other extreme, one could obviously say that patient choice is maximized by the provision of free health care. However, it may be a restriction of choice in that some may prefer not to get so much health care and be unwilling to contribute resources towards the state to maintain the system at the expense of other uses of tax revenue or lower taxes.

Health care systems can also be compared on patient choice in terms of getting what the patient needs and what the physician judges to be medically indicated. In the system that the U.S. currently has, complaints about limitations on patient choice concern not just affordability but the ability of the health care delivery system to enable patients to see the doctors that they want and to get the options of treatment to choose from. The fact that whether patients get health care from the state or from private insurers, they are limited in their choice of physicians and treatments and are denied options deprives patients of full autonomy. Nevertheless, the restrictions on choice may be morally justified and one way to see this is that similar restrictions are unavoidable even if the current system is reformed in the direction of either of the two extreme positions.

II

The classic libertarian view espouses a minimum of state interference in personal choices, in particular in how personal wealth is acquired and transferred. The principles of justice in libertarian theory are justice in acquisition and justice in transfer of private property.² The role of the state is to protect individuals from interferences that deprive them of their freedom and rights to justly dispose of their wealth as they deem fit. To achieve justice on these terms, libertarians seek to get the state out of the activities of providing health care and of regulating the health care industry. For the state could only provide health care by using resources that it acquires through taxation and the libertarian views such a system as coercive and a form of enslavement whereby individuals are deprived of the rewards of their work. It should be the choice of individuals whether they wish to use their material resources for their own health care, and how much to use. They also have the choice of charitably providing health care for other people but the state should not enforce charity or a redistribution of wealth.

What about those who do not have the resources to pay for needed health care? Without the state providing health care, they will have to do without or depend on charity. Is that fair? Is that a loss of autonomy? On the libertarian view, the inability to purchase health care is the result of the individual's own choices. Like other goods, health care is something that a person should acquire material resources to pay for. Since it is expensive, people need to earn enough to put aside money or buy insurance for the contingency of falling sick. The purchase of health care is a voluntary exchange whereby the earnings that a person gets for his work is used to pay the physician for providing health care services to get the person well. In other words, there is no right to health care, only what one deserves based on the contributions one makes through one's work.

Those who do not get health care are not unjustly deprived.

The libertarian idea of free exchange of goods is linked to the idea of free markets that distribute resources and wealth according to the value individuals place on goods. Free markets are thought to direct resources to users who value them the most thereby maximizing the productive use of resources. The end result would be that better goods are produced at lower cost and more people are able to afford the goods. Thus, free markets reward innovation and hard work and improve the quality of life. The technology sector of the American economy is held to be an example of how the rewards for private entrepreneurship motivates industry and raises standards of living.

Whatever one might think of unbridled *laissez faire* capitalism, there remains the question of whether the libertarian ideal works for health care. First, facts and statistics comparing the U.S., which only has state-provided health care for seniors, veterans, and the very poor (Medicare, VA, Medicaid), with the majority of Western industrialized countries that have national health care systems show that the U.S. spends a lot more but gets worse results in health care. Some economists may point to imperfections in the market and state intervention as the cause.³ But even those who favor the capitalist system of private incentives for other goods may have reason to be skeptical of the application of the libertarian model for health care. There are many goods that it is morally acceptable for people to do without or with less. Nobody dies or suffers physically for not having a television or a microwave oven. Is it right that a patient is refused treatment that she cannot afford and dies as a result? It is true that happens in very poor countries or in the aftermath of disasters. But under libertarian principles, such refusal would take place all the time everywhere in the health care system.

Furthermore, is it true that those who cannot get health care deserve it for not earning and saving what is needed to pay for health care? It is a fact that the cost of lots of health care today goes beyond the ability of most Americans to pay for from what they earn, even in a lifetime.⁴ Moreover, health problems can strike at any time in a person's life and the nature of the problems cannot be foreseen. It is impossible to plan for or to know how much one needs to have to pay when illness strikes. This is the reason that health insurance is necessary. But if we assume that the premiums that insurers charge reflect the average cost of the average person to receive needed health care in a lifetime, and we compare that with what people earn for the work that they do, the unavoidable conclusion is that health care is beyond what a majority of Americans who have jobs can afford to pay for. In what sense do they not deserve health care if there is nothing they can do to acquire the resources to pay for health care?

What I think is behind the libertarian faith in the market solution to justice in health care is a failure to appreciate the kind of good health care is, how much it costs, and how it is provided. The principles libertarians espouse would work if health care could be afforded by almost anybody with a job. This might have been almost true two hundred years ago when health care meant a visit or two to the town doctor. If that does not get you well, there is little more that can be done to avoid the patient's demise. Compare that with the treatment of any serious illness today where repeated hospital visits are needed and several doctors have to be consulted. Growth in earnings in recent times is far from keeping pace with inflation in health care costs and the gap has been trending wider.⁵

III

The principles of liberal political theory are best articulated in the work of John Rawls.⁶ The principles of justice that govern particular institutions, laws, and policies are derived from a

social contract behind a "veil of ignorance" eliminating any personal knowledge that could motivate a preference for rules that unfairly favor oneself. Rawls is concerned with the distribution of "primary goods" that every rational person is presumed to want and have a use for, whatever her rational plan of life is. These goods include liberty and opportunities to hold positions of authority which, according to the principles of justice, should be distributed as equally as possible. The Difference Principle applies to income and wealth. It is a principle that requires social and economic institutions to be arranged so as to benefit maximally the worst off in society. This is not a requirement for equal distribution, but distinguishes between justified and unjustified equalities. It is just for some in society to have more income and wealth than others if this inequality improves the condition of the worst off in society. For instance, an innovator may be rewarded for his inventions and is justified in getting more because the inventions improve the lives of the worst off, for instance, as a tool of education. Likewise, doctors improve the health of the community including the worst off so they may be justified to earn more.

Rawls does not mention health care as a primary good, but there are those who argue that it could or should be.⁷ If health care is distributed together with other primary goods according to the Difference Principle, then we need to be concerned about what the worst off receives. Although it will not be equal to everybody else, what they should receive is the greatest share of primary goods they could get in a system without unjustified inequalities. Given the wide inequalities of wealth and income in the American economy, the Difference Principle can be applied to justify the removal of a part of the wealth held by the rich for the purpose of increasing the share of primary goods that the worst off receive. The state can achieve this by taxing the rich and using the resources for the benefit of the worst off in terms of education, health care, and other services that improve their opportunities in life. How much of the primary goods redistributed in the form of health care would depend on how health care is weighted in relation to other primary goods. Given that left to the free market, the rich will hold more wealth and the worst off have less or no health care, the state's intervention to ensure a decent minimum of health care for the worst off in society is justified by Rawls' liberal principles of justice even if it goes against the freedom of the rich to do what they want with their money.

Clearly, most people will have access to some health care in a liberal state. Will it be everybody? And will it be everything they need or want? One of the features of political liberalism is that it does not impose an idea of the good life for everybody. This means that citizens are free to choose their own life goals and conceptions of happiness. Some of these may require more use of health care than others. Someone may not be happy until she wins a beauty contest. Should she be provided with cosmetic surgery? Someone wants to have more body strength to succeed as an athlete. Would steroids be provided? And if someone wants to be a mother at age sixty, should she be given assisted reproductive services to achieve this?

Clearly the state would have to limit health care choices and guarantee only a certain standard. For a wealthy nation like the United States, it does not have to have a bare minimum. Nevertheless, there are still limits given that resources are finite and there are other needs. But pushing against these limits are the demands made possible by medical technology. There is also the changing demography in which an aging population requires health care of the more expensive kind. The concept of old age has also evolved into one that sees it as normal for retirees to have active lifestyles and medical science is supposed to make it possible. It is not surprising that seniors

would place more weight on health care than on education in the index of primary goods. By drawing a line based on resources and other essential needs, the state will have to refuse to satisfy patient choices that go beyond what can be provided for everyone, leaving a large portion of health care to be distributed according to the ability to pay. Only a very few will get everything they want. But unlike in the libertarian system, the state will ensure everyone gets some health care.

IV

The discussion so far shows that whichever theory of justice one accepts, some limitation on patient choice is required. Given the nature of health care and the practice of medicine today, maximizing choice (whatever that means) cannot be achieved if health care resources are to be distributed fairly. Even in socialized medicine, patients do not get everything they want (and may get less than in a free market for health care). In the light of the theoretical discussion above, I shall now discuss whether some of the restrictions on choice that result from the Patient Protection and Affordable Care Act signed into law by President Obama in March 2010 satisfy the requirements of justice.

The so-called Obamacare falls in between the libertarian and liberal positions, though it is perhaps nearer to the latter. As there is no public option, health care insurance will continue to be purchased from private HMOs. Thus, it is not guaranteed that every citizen will receive a basic amount of health care. However, the health care reform law does envisage insuring about 30 million of the currently 50 million uninsured Americans by preventing insurance companies from denying care on the basis of pre-existing conditions, forcing them to lower rates to compete on health care exchanges, and providing subsidies to employers and individuals who cannot afford even the lowest rates on the market. Thus, some tax money is used to help the worst off in society and the business activities of private insurers are regulated to some extent. In addition, individuals will be mandated to get insurance or pay a tax penalty. Those who do not want to purchase insurance as they are betting on not getting sick will be coerced into getting insurance so that they do not become an unpaid liability on the health care system when they do get sick. Moreover, by enlarging the pool of the insured with healthy individuals, there is greater risk-sharing with the less healthy, which would allow insurers to avoid raising premiums sharply to cover those who need health care.

Opponents of the PPACA health reform argue that people should have the freedom not to buy health insurance. But under libertarian principles, these people should not get health care if they fall sick and are unable to pay. What is likely to happen is that these people will use emergency rooms to get free health care. In fact, the services provided in emergency rooms are meant to help the worst off in society under liberal principles of justice. Would libertarians prevent the uninsured from using free services paid for by the taxpayers? Is this compatible with non-interference with individual choices?⁸ But under liberal principles, those who earn enough to have more than the worst off should contribute their unjustified inequalities if any to pay for services to help the worst off, such as emergency rooms. So to require them to purchase health insurance is to require them justly to contribute to health care that they could use one way or another if they fell sick. Neither theory of justice considers it to be just for a wage-earner not to pay to get health care. Unless emergency rooms deny service to those who cannot afford to pay, the individual mandate seems to be required by justice.

Another objection to the health care reform law is the mechanism proposed to keep costs down by not paying for unnecessary care. In some hospitals, studies have shown that additional tests and treatments have cost more without

improving patient survival and recovery rates. The best practices in treatment and care for patients will be selected and paid for but patients will not be able to choose those treatments considered not to be medically indicated. Under libertarian principles, the limit on what patients as consumers get is what they can pay for. But whether health care is paid for by insurance companies or by the state (in the case of Medicare), it is appropriate to cover only the most effective treatments. Perhaps patients should have the option of paying higher premiums to get more treatments covered, but that is exactly what is available in private insurance and the PPACA relies on private insurers to provide health care. Under liberal principles, the state can guarantee a decent minimum of health care but not everything a patient wants. So there does not seem to be injustice on either theory with the denial of unnecessary and costly health care by a health plan, especially if the denial is based on medical science.

Finally, consider the objection that the involvement of government reduces choice for consumers of health care as private insurers are squeezed out of the market. The public option was removed from proposals for health care reform that culminated in the PPACA by critics who saw it as taking business away from private insurers. There are obvious reasons why private insurance would be unable to match the cost of health care provided by the government. The state does not need to make a profit for shareholders and it does not have to spend on marketing and the selection of enrollees. Comparisons made between the U.S. and advanced countries that have national single-payer health care show administrative costs to be much higher with private insurance. But if citizens are unable to purchase health insurance from private insurers because the state is able to do it at lower cost, it is perverse to object. The whole point of touting a free market for health care was to lower costs on the assumption that competition fosters efficiency and a better product. The value of choice in health care is to be able to achieve the basic goals of health care, that is, to have access to health care resources when one needs to get well. The state and private insurers are different means of making health care available. Autonomy is harmed when one has no means of getting health care but this is not the case if private insurers are eliminated from the market by a more efficient state system. On the other hand, autonomy is harmed when one cannot get access to basic health care, which is the case for up to 50 million Americans who have no private health insurance.

What becomes clear from this discussion is that justice in health care does involve some justified limitations of choice. But that is precisely what justice has always been about, whether it concerns health care or other goods in society. Justice is needed to ensure that people have their basic needs met and basic rights respected. If justice requires that the choices of some people are restricted, even Mill I think would not object since he thought that liberty could be constrained to prevent harm to others.

Endnotes

1. American Medical Association, *Code of Medical Ethics: Current Opinions with Annotations* (2002 edition), [my emphasis].
2. The principles of libertarian political philosophy are found in Robert Nozick, *Anarchy, State and Utopia* (New York: Basic Books, 1974).
3. Others may point out that it is not only health care but almost every market fails to replicate the free market ideal so there is a question regarding the real-world applications of free market capitalism.
4. Take, for instance, the case, reported in *The New York Times* (Dec 2, 2010), of Francisco Felix, 32, a father of four who had hepatitis C and was in need of a liver, but was not given a

liver transplant after Arizona stopped Medicaid financing for transplant operations and he was unable to raise \$200,000 to pay the hospital. How many working people would have that much in savings at the age of 32?

5. I am presenting these facts as challenges to the application of libertarian principles to the health care market, but more than facts are needed to challenge a libertarian mindset that assumes people who cannot afford anything have only themselves to blame and should not expect anyone else to provide them with it. In other words, libertarians may dispute the claim that there are historical and social explanations for anyone's inability to afford health care, or for poverty in general.
6. John Rawls, *A Theory of Justice* (Cambridge, Mass.: Harvard University Press, 1971).
7. E.g., Allen Buchanan, "Justice: A Philosophical Review," *Justice and Health Care*, edited by Earl Shelp (Dordrecht: Reidel, 1981), 3-21, and Norman Daniels, *Just Health Care* (Cambridge: Cambridge University Press, 1985).
8. Libertarians may not view the denial of emergency care as a limitation of choice but favor a market price for such services. They may view free emergency services as a matter of charity and see no role for the state in making such services available. The lack of free services may put market pressure on individuals to purchase health insurance, especially when people start dying from inability to get health care. Thus, my point that if people are not required to buy health insurance, some would suffer the consequences when they fall sick need not bother a hard-nosed libertarian.

Hegemony and the Health Care Debate: A Post-Marxist Analysis

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I. Contextualizing post-Marxism

Ernesto Laclau and Chantal Mouffe formulated a general theory of society in their monograph, *Hegemony and Socialist Strategy*; the theory was subsequently dubbed "post-Marxism."¹ Their analysis revolves around the concept of "hegemony," which, they argue, is the political process by which social identities, movements, and myths are formulated. More precisely, "hegemonization" occurs when one group or faction represents increasingly more of and, ideally, all of society.

Post-Marxism departs from Marxism in significant ways. Laclau and Mouffe describe the theoretical distance between the two as an ontological one: where Marxist inquiry has been carried out under the paradigms of Hegelianism and naturalism, post-Marxism, as its prefix implies, relies upon poststructuralist thought.² Thus, though post-Marxism shares some common terminological territory with traditional Marxism, each assigns different meanings to, for example, "contradiction" and "ideology."

Despite its innovations, post-Marxism retains certain connections with traditional Marxism, and I think two are worth mentioning here in the interest of understanding the former. First, Marxist scholarship comprises a large part of Laclau and Mouffe's intellectual heritage. It might be objected that this is a merely contingent connection, given that anyone's scholarly starting point is somewhat accidental. It might be argued that the concept of hegemony could have arisen out of a different tradition with a different set of problems. However, this observation does not provide us with insight into their theory and, in fact, it relies on an essentialism that Laclau and Mouffe reject.³ *Hegemony and Socialist Strategy* develops a

genealogy of Marxist thought that demonstrates its explanatory inadequacies, namely, essentialism and determinism. What goes by the name of "post-Marxism" constitutes Laclau and Mouffe's solution to these inadequacies and can be best understood within these parameters.

Second, post-Marxism, like Marxism, approaches social theorization in a reflexive posture. This might also be termed a "critical" posture, as it is a defining feature of the German idealist tradition that is widely recognized to have begun with Kant's *Critique of Pure Reason*. Critical philosophies give pride of place to the insight that human thought is both unconditioned and conditioned. This insight goes hand-in-hand with the transcendental approach to metaphysics and epistemology, which begins with the conviction that we cannot escape reliance on "the world as we find it"—that is, thought requires that there be experiences of self and world that appear to be "ready-made" for us, already put together in a comprehensible way. The transcendental method begins also, however, with the recognition that the object of inquiry is *human* thought and *human* experience, and this means that our experience of self and world can never be an unmediated one. This sort of inquiry will proceed, then, by granting legitimacy to some aspect of "the world as we find it," then asking what conditions, limits, constraints must be in place in order to produce that world.

For their part, Laclau and Mouffe begin with the phenomenon of "*political* articulation" and assert "that the central category of political analysis is . . . *hegemony*."⁴ That is, they regard the process by which new political ideas, myths, and identities are created as, for lack of a better term, *real*. Political movements do form, political unities are forged, myths emerge, concepts do take hold of the public imagination—and hegemony is the mechanism by which they successfully do so. The transcendental question that motivates Laclau and Mouffe's theory, then, is "how . . . does a relation between entities have to be, for a hegemonic relation to become possible?"⁵

II. Elements of a theory

Laclau and Mouffe's concept of hegemony rests on an analogy between "society" and "language." This approach has its origins in semiotics, which expanded the application of Saussure's structuralism from its original focus on linguistic grammar to any signifying element (that is, any element of meaning). "Discourse" is Laclau and Mouffe's term for this field of potential and realized meanings. Discourse indicates "any complex of elements" whose identities are constituted by their relationships with other elements.⁶ Discourse is derived in a fairly straightforward way from Saussure's relational theory of meaning. According to this theory, the meaning of a sign consists in its opposition to other signs within a system. This means that the sign itself has no intrinsic meaning.

Poststructuralist theorists have, of course, modified structuralism in a number of ways since its inception, and one of these modifications is especially relevant to the theory of hegemony. Saussure's development of the "science of linguistics" led him to posit a closed system of signs, which implies a certain kind of determinism: although the elements are defined in relationship to each other, the unchanging nature of the structure would give those relationships a necessary quality.⁷ Derrida, for one, argues that any system or structure must be open; its constitutive rules cannot be impervious to mutation.⁸ An "open" structure implies the potential for perpetual shifts of meaning as signs may come to have different oppositional relationships. Thus, only an open structure can account for the emergence of new political ideas, identities and movements, and freedom. The conceptualization of social and political structures that have no ultimate essence permits Laclau and Mouffe to theorize what they call practices of *articulation*.

These establish new relationships of opposition among the terms of a structure, new ways of thinking and being.

The “nonessential essence” of political identities and movements poses a theoretical challenge, for if the mythical center were indeed located outside of the identity or discourse, it would be one more opposition to the terms of that identity or discourse. That is, if what lies beyond my identity is opposed to my identity, then it is, paradoxically, constitutive of my identity according to a relational theory of meaning. Hegemony cannot therefore be explained only in terms of the “logic of difference,” that is, those articulations that make meaning by establishing differences between terms. Differential relations alone cannot establish the limits of an identity. Laclau and Mouffe supply this limit in their account of the peculiar nature of the status of what lies on the borders of an identity.

Each term within a discourse has what Laclau and Mouffe call a “positive identity.” This just means that it is relationally defined, its meaning is unambiguous. By contrast, the elements that lie beyond the limits of a discourse have what might be called a “negative identity” (*vis-à-vis* that discourse). Their identity is negative in the sense that, from the perspective of the (positively defined) discourse, the elements lack definition.

Articulations that place these “meaningless” elements at the “borders” of a discourse follow what Laclau and Mouffe call “the logic of equivalence.”⁹ In equivalence articulations, an enemy is located and named as a term that stands against the “positive” or defined terms of the political identity, platform, or myth. These terms have a merely nominal significance *vis-à-vis* the terms of the discourse they stand in relationship to. The “meaning” of these “meaningless” signifiers within the discourse is simply “not us.” Because they remain undefined, they can serve to stabilize identities and discourses without being incorporated into those identities as another difference. In other words, by including what I am not as part of my identity, I establish the boundaries of my identity.

This means, however, that equivalence terms have a dubious status: they are both *internal* to an identity, in the sense that they are constitutive of the identity, and *external* to it, in the sense that they are “not-*x*.” That is, a discourse achieves its distinction by means of its internal differences, but also in its distinction from what it is *not*. And the simplicity of the label “not-*x*” obscures—or, in Laclau and Mouffe’s term, *dissolves*—the “positive” aspects to identity. That is, the inclusion of what lies beyond my identity renders my identity particularly vulnerable to mutation. Ironically then, the same articulatory maneuver that enables identity is also that which destabilizes it.¹⁰

In naming what lies at the borders of significance, equivalence maneuvers designate a “space” that, Laclau and Mouffe maintain, is a basic feature of political agency. That “space” is the sense of incompleteness that is integral to identity or meaning. Equivalence relations are built around this space, and locate—or rather, *accuse*—a source of that felt incompleteness. That is, they give name and face to one that I will thereby come to view as my antagonist, who becomes the “enemy within.” The presence of this enemy poses a perennial threat to my identity, and precludes “wholeness.”

Let’s return to Laclau and Mouffe’s starting point, the puzzling phenomenon of hegemony: How can one movement or party come to represent the interests of society at large? How can the part become the whole? Hegemonization is possible only because no identity or party will ever be able to have a “complete” identity, one that is protected from subversion. In other words, hegemony is possible because “society” as a closed system is impossible, because terms like “freedom,” “patriotism,” and “government” have no final definition.

These terms and others are available for incorporation into the discourse of any political group by means of articulations of difference and equivalence. Hegemonic articulations aim to expand political territory by including more and more political interests under one banner. I hope to demonstrate here the ways in which conservative Republicans attempted to hegemonize the meaning of “national health care” using articulations of equivalence and difference. I will also discuss the Left’s responses and diagnose, in hegemonic terms, where Leftist discourse failed.

III. The anatomy of the health care debate

Republicans’ primary tactic in the health care debate was to heighten the anti-Statist rhetoric that has so successfully unified their constituency since the Reagan years. The political power of this equivalence articulation (that is, anti-Statism) lies not only in its ability to stabilize the Republican platform. It also has an “enlarging” effect typical of hegemonic articulations. In identifying themselves as “opposed to Big Government,” Republicans are attempting to extend the reach of the party by identifying an enemy. If successful, this has the effect of appealing to those who object to bureaucracy; to put an even finer point on it, it provides the public with an opportunity to object to bureaucracy. This opposition was deployed preemptively in the health care debate: before reform efforts had begun in earnest, before Democrats had even submitted a proposal, Republican leaders referred to the specter of the proposal as a “government takeover of health care.”¹¹ This characterization continued throughout the debate and survived the passage of the reform bill. In a brief response to the passage of the bill, Republican Mike Pence stated that “House Republicans . . . are determined to continue to take our case against this government takeover of health care to the American people. . . . The American people oppose a government takeover of health care.”¹² The meaning of “government” here, as well as its capacity to pose a threat, are both given a very truncated elaboration by the Right. Of the many available meanings that “government” has assumed or might assume, its meaning within conservative Republican discourse derives only from its contrast to that discourse. Within that discourse, the individual’s freedom is paramount, where “freedom” is understood in classically liberal terms.¹³ “Government,” then, signifies *only* what would undermine this privilege: “invasive,” “patronizing,” and “arbitrary.” In Laclau and Mouffe’s terms, “government” *antagonizes* the conservative identity; it is merely an obstacle to the actualization of the conservative identity.

The anti-Statist maneuver included familiar Right-wing rhetoric, slightly modified to accommodate the issue at hand. For example, Republicans repeatedly invoked the threat of economic stagnancy that, they assert, accompanies state oversight. A member of John Boehner’s staff, for example, referred to the successfully passed reforms as “the Democrats’ job-killing takeover bill,” while Pence’s response promised continued Republican opposition to the “job-killing tax increases” that the bill would impose.¹⁴ Moreover, Republicans continued to make such accusations in spite of President Obama’s rebuttals, and with no recognition that both parties were in uncharted territory. In doing so, they relied on an equivalence strategy that has worked for them time and again; in this incarnation, it aimed to fix the definition of health care reform by casting it as the enemy of a healthy economy. It did so by incorporating “health care reform” into an already-existing chain of equivalences whose terms signify only “that which the Right stands against.” Articulations of this sort do not follow the rules of reason, but the rules of discourse. Boehner, for example, attacked a House reform bill based on its length. “All you need to know is there are 1,990 pages. . . . That should tell you

everything.”¹⁵ Lee Terry, another Republican Representative—and a lawyer—complained about the language of the bill on the grounds that “it’s written in legalese.” Clearly, Republicans have grasped that the impact of rhetoric does not lie in its rational consistency. Rather, its appeal lies in the promise to hegemonize; to fix the meaning of terms that cannot be fixed, to simplify issues that are hopelessly complex, and to bring closure to identities that are constitutionally open to change. For Republicans, this fixation is accomplished by amplifying an antagonism, thereby unifying their base against the enemy: Big Government.

In their opposition to Democrats’ proposals for health care reform, Republicans opposed measures that would insure all Americans, proposing instead programs that would reinscribe inequality. These counter-measures included such features as permitting insurance companies to provide across state lines, or to create high-risk pools. The former would presumably increase competition and lower costs, but would likely be accompanied by a decrease in quality of care. The latter would effectively penalize those with health conditions by charging them outrageous premiums. At the same time, Republicans employed populist language in their rejection of reform. Pence’s response, for example, cited Alexander Hamilton’s words: “here sir, the people govern.”¹⁶ While both Republicans and Democrats presume to speak in the name of the American people, the reforms proposed by Republicans would have benefitted the few, and were thus antithetical to the spirit of populism. The theory of hegemony is able to explain the transformation of populism such that “the will of the people” no longer derives its meaning from opposition to the wealthy, as it did in the early twentieth century. Right-wing populism depends upon antagonism between the many average citizens and Big Brother—the State that micromanages its citizens. This strategy was evident in Senator Mitch McConnell’s remarks following an early vote on health care legislation, in which he described the Democratic approach to reform as “this sort of arrogant approach that everybody sort of shut up and sit down, get out of the way, we know what’s best for you.”¹⁷

Two of the Right’s more potent attacks cast the government as an enemy to one of our most basic liberties—our bodily integrity. In the midst of the health care debates, a government panel proposed new guidelines for mammography tests, which pushed the recommended age for regular screenings back from forty to fifty, and from every year to every other year. Republicans’ interpretation of these guidelines was accomplished by two discursive maneuvers. First, they established a connection between the guidelines and the concept of “rationing.” In fact, a group of Republican congresswomen held a press conference specifically to “warn that access to mammograms could be restricted.”¹⁸ Representative Jean Schmidt commented, “that’s why I was so outraged by it . . . every year, I’m allowed to have a mammogram, because that’s what the recommendations are. My fear is it’ll be every two years, and then maybe every three years.”¹⁹

Interestingly, the elaboration of the meaning of the guidelines according to the logic of difference—by articulating them to “rationing”—is only one piece of the puzzle, for “rationing” is not inherently a threat, and not sufficient to provoke outrage. Indeed, rationing efforts, for example, during WWII, have historically been connected to patriotic sentiment, manifesting an allegiance to the general welfare over individual privilege. Schmidt’s expression of outrage indicates an antagonism and thus adheres to the logic of equivalence, drawing attention to the threat of encroachment by a faceless bureaucracy on the private sphere. The new guidelines, Republicans claimed, illustrated the way in which the government could intrude upon

the doctor-patient relationship, curbing the individual’s right to determine what kind of care she needs.

Another equivalence maneuver, articulated early on in the debate, established this same opposition: on the one hand, the individual’s right to bodily integrity and to the prescriptive authority of her doctor, which are taken to belong to the private sphere; on the other hand, the government, which would limit the freedom of individuals (doctor and patient) by limiting access to resources, with potentially fatal consequences. This time, Republicans warned that according to a pending House bill, “Congress would make it mandatory . . . that every five years, people in Medicare have a required counseling session that will tell them how to end their life sooner, how to decline nutrition.”²⁰ Former vice presidential candidate Sarah Palin was responsible for giving this mythical measure its inflammatory name: the “death panels.” One conservative news outlet even compared the death panels to Nazi programs that euthanized the disabled.²¹ The measure, which in fact provided for *optional* end-of-life counseling, was dropped from the bill. The effectiveness of the “death panels” epithet, however, did not consist in the exclusion of optional end-of-life counseling from the bill, or even in the accuracy of the title. A hegemonic maneuver such as this is effective if it successfully fixes the terms of the debate according to the articulation; if, that is, it convincingly establishes that Democrat-led health care reforms are symptomatic of a totalitarian threat, and wins adherents to conservatism on the basis of that equivalence articulation.

The specter of “death panels” also served as ammunition in a second type of equivalence maneuver: that of establishing health care reforms as a promotion of the “culture of death.” The idea that Democrat-led reform would lead, at worst, to euthanizing the elderly or at best, to public acceptance of euthanasia, was fueled by conservative Jim Towey, “director of the Office of Faith-Based Initiatives under George W. Bush.”²² A *Wall Street Journal* op-ed written by Towey claimed that “a 1997 workbook from the Department of Veteran Affairs,” which had been out of circulation for two years, “pushes vets to ‘hurry up and die’.”²³ Equivalence maneuvers typical of the culture wars aim at polarizing voters by offering them the choice between “x, what we, the Republican party offer,” and “not-x, offered by liberals.” In such a formulation, the latter is not simply opposed to the former, but poses a threat to the former. In this case, Republicans sought to reinforce their socially conservative ranks by drawing attention to the ways in which health care reform threatens the valuation of life as such. This maneuver may have led to more widespread rejection of health care reform on the basis of its immoral implications.

A similar Republican strategy attempted to enlist the pro-life movement in its rejection of reform. Throughout the debates, Republicans made it clear that they would oppose any bill that provided federal funding for abortions. Indeed, referring to the bill during Congressional debate, Republican Representative Randy Neugebauer, shouted “It’s a baby killer!” from the House floor.²⁴ Fanning the flames of the abortion debate here followed the same pattern as other battles in the culture wars: it targeted citizens “on the fence.” There are a number of moderate Catholics, for example, who favor public policy that offers relief to those in need, as universal health care would, but who also oppose abortion. In drawing attention to the possibility that a health care bill would provide public funding for abortion, the Right drew attention to an antagonism between these moderates and pro-choice Democrats. If these moderates had joined the Right in their opposition to health care proposals over the abortion issue, it could have proven fatal to the reform effort.²⁵ It would have also meant that the Right had successfully hegemonized the

meaning of health care measures by means of an equivalence maneuver. That is, the Right would have successfully fixed the significance of health care reform in accordance with their agenda; they would have convinced enough of the citizenry to achieve political gain.²⁶

Of course, it is not only Republicans, but Democrats who are involved in hegemonization efforts. The Obama administration tried to link health care reform, first, to fiscal responsibility, and second, to social democratic ideals such as economic equality.²⁷ Framing the issue in terms of fiscal responsibility amounts to an attempt to seize Republican territory, as “fiscal responsibility” is generally understood as a plank in the Republican party platform. President Obama’s call for fiscal responsibility hinged on establishing an opposition to those who profit by driving up costs: insurance companies. One of the administration’s top advisors, for example, characterized insurance reform as protection against “the sort of mercurial judgments of insurance bureaucrats.”²⁸ Under the umbrella of this opposition, the administration could appeal to Republican voters without refuting the party’s claims; a refutation would put the disagreement in Republican terms and thereby give them a home court advantage. By contrast, Democrats’ equivalence maneuver located a new enemy to the nation’s financial health: Big Business, and not, as Republicans would have it, Big Government.²⁹

The Obama administration had to tread lightly in articulating its vision of social democracy, given the success of the Right’s image of “tax and spend” liberals as the chief promoters of a bloated, expensive, and inefficient state. This picture is associated with Democrats’ historical support of programs that redistribute resources in a way that aims to empower the disenfranchised. Consistent with this record, President Obama continued to assert the importance of universal access to affordable health care. However, he combined his message with the promise that reform would reduce the deficit, and that most Americans’ taxes would not increase. In this way, the administration sought to reinterpret its party’s traditional commitment to social justice as compatible with a sensible budget.³⁰ This articulation seeks to win voters by inclusion, not exclusion; by dissolving antagonism rather than building around it. Specifically, it follows the logic of difference, and takes aim directly at conservatives’ equivalence discourse in which “Democrat” signifies one who is hostile to a state that lives within its means.

Despite their own hegemonic effort, many on the Left remained baffled by right-wing strategies and responded to them in ineffectual ways: dismissing the Right’s political plays as absurd, trying to reason with the Right, or analyzing its ideology for inconsistencies. For example, in response to the most extreme “death panels” accusations—those that compared the proposed reform measures to Nazi programs—former Senator Tom Daschle confidently claimed that “almost automatically, you have most of the audience on your side. . . . Any rational normal person isn’t going to believe that assertion.”³¹ Daschle is probably correct in his belief that if the average American is asked whether Democrats are in favor of exterminating the elderly, she will respond in the negative. But this fact cannot account for the impact of what is a polemical comparison between Democrat-proposed reform measures and the programs of a totalitarian regime, for the weight of “bare facts” is determined within discourse. Health care reform likewise gains its significance from the discourse in which it is embedded, and discourse is constructed by successful articulations that establish differences and equivalences between “health care reform” and other terms. The Right’s claims, even if false, have the potential to link Democrat-led reforms to a totalitarian state,

and it is with reference to articulations such as these that health care reform will be meaningful for the public.

Consider also President Obama’s meeting with Republicans in January of 2010, after the health care debate in Congress had become intractable. The meeting was ostensibly an attempt to reason with Republican members of Congress who seemed opposed to reform as a matter of principle, in the hopes of reestablishing some bipartisanship. The President opened the meeting remarking,

I’m looking forward to taking your questions and having a real conversation. . . . And I hope that the conversation we begin here doesn’t end here; that we can continue our dialogue in the days ahead...It’s only through the process of disagreement and debate that bad ideas get tossed out and good ideas get refined and made better. . . . I want us to have a constructive debate.³²

These comments are consistent with the interest in bipartisan cooperation and dialogue that Mr. Obama expressed as a presidential candidate.³³ Yet a hegemonic analysis explains why the President’s efforts are unlikely to pay off in light of the strategies employed by the Right. The Right’s ideology is not dialogical; its purpose is not a refinement of ideas through critical exchange. Rather, it is hegemonic; its purpose is to control an ever-larger portion of political territory by shaping the discourses within which social identities, values, activities, and resources become meaningful.

Where the Left does not assume that Republicans will act rationally, it continues to assume that they *should*. In a scathing critique of the right-wing rhetoric surrounding the health care debate, “based mainly on lies about death panels and . . . that reform will undermine Medicare,” Paul Krugman finds Republicans’ defense of “unrestricted Medicare spending” blatantly inconsistent with their ideological commitment to small government, and to their track record on this issue since the 1980s.³⁴ Krugman observes that Reagan, the hero of

the modern Republican party . . . was a fierce opponent of Medicare’s creation, warning that it would destroy American freedom. . . . In the 1990s, Newt Gingrich tried to force drastic cuts in Medicare financing. And in recent years, Republicans have repeatedly decried the growth in entitlement spending that is largely driven by rising healthcare costs.³⁵

According to Krugman, the GOP has abandoned *its own party identity*, an identity well-established over the last thirty years, in assuming the role of “defender of the social safety net.” Krugman looks for, and fails to find, coherence in this position. Again, the theory of hegemony emphasizes that political identities are fundamentally subject to change. That “Republican” gains its meaning from a discursive formation makes some maneuvers more likely than others, some options more “live” than others. However, that formation is essentially open to mutation, making even “contradictory” articulations possible. In this instance, an equivalence relation targets the Democrats’ health care plan as an enemy to seniors’ quality of life. This is a way of giving significance to health care reform. There is not one way, but several ways to understand health care reform; the theory of hegemony explains how, for the purpose of advancing a political project, different groups try to fix the significance of terms so that it *appears* that that meaning is *the* correct one.

I have tried to show that the debate over national health care provided one more opportunity for the GOP’s ongoing attempt to hegemonize all segments of American society,

including those who are harmed by its policies. Laclau and Mouffe's theory of hegemony enables a subtle description of the maneuvers employed by Right and Left in the debate, thereby enabling an explanation of the Right's persistent and widespread appeal as well as the Left's largely ineffectual politicking.

Endnotes

1. Ernesto Laclau and Chantal Mouffe, *Hegemony and Socialist Strategy* (London: Verso, 1985).
2. *Ibid.*, x.
3. Namely, it relies on the presumption that a theory or concept has a "free-floating" (as it were) essence that can be formulated independently of any particular vocabulary or tradition. An alternative "understanding of understanding" would be that theories and concepts can only be grasped against the background of the context in which they appear.
4. *Ibid.*
5. *Ibid.*
6. Ernesto Laclau, *On Populist Reason*.
7. For example, we may suppose the game of chess to be eternally unchanging. Each game may still be different, but the elements, the pieces and the possible moves each can make, are defined once and for all by the constitutive rules. This might be described as a functionalist determinism.
8. Briefly, Derrida points out that every system is built around a sign that functions as its center, as the term that gives all other terms meaning. This generates a paradox as the meaning of the center is both a term within the system (and should therefore have meaning according to the same relational logic as the other terms) yet insofar as it gives meaning to every other term, its meaning must transcend (be derived from without) the system. This implies an open system, one that cannot generate all meanings from within.
9. Laclau and Mouffe's distinction between the logics of difference and equivalence riffs on Saussure's designation of two types of relations that can obtain among signs: syntagmatic and paradigmatic (or associative). The former are linear relations that link signs in a chain—the relations between signs in a sentence, for example. These arise as a matter of fact—you cannot pronounce two words simultaneously. The latter are relations of similarity; they subsist between terms that have a graphic or syntactic commonality—for example, the relation between "power" and "tower," or between "power" and "force." Poststructuralist thinkers beginning with Roman Jakobson extend these concepts beyond structural linguistics to characterize types of discourse. A discourse may be *metonymical* (corresponding to syntagmatic relations) or *metaphorical* (corresponding to paradigmatic relations). Briefly, metaphorical discourses establish similarities among their differences, which can lend itself to substitutions of differences. These relations predominate in richly symbolic texts.
10. "Vis-à-vis the excluded elements all identities antagonised by it are not merely differential but also equivalent, and equivalence is precisely what subverts difference. So that which makes difference possible is also what makes it impossible." Ernesto Laclau, "Philosophical Roots of Discourse Theory," University of Essex, <http://www.essex.ac.uk/centres/TheoStud/onlinepapers.asp> (March 12, 2009), 5.
11. Jill Jackson, "House Republicans Offer Health Care Plan," CBSNews, June 17, 2009, http://www.cbsnews.com/8301-503544_162-5093897-503544.html (May 2, 2010).
12. GOP.gov Press Release, "Pence: 'One More Speech About the Same Bad Bill Isn't Going to Change Any Minds in America,'" GOP.gov: Press Release, March 23, 2010, <http://www.gop.gov/press-release/10/03/23/pence-one-more-speech> (March 29, 2010).
13. I have described these terms above; briefly, this is a *laissez-faire* ideal according to which the individual has sovereignty over his private property.
14. Marin Cogan and Glenn Thrush, "In Wake of Health-Care Debate: Was GOP Response Ugly Politics or Reaction to Dems' Arrogance?" *POLITICO*, March 23, 2010, http://www.twincities.com/allheadlines/ci_14739861 (March 29, 2010). Pence's response cited above in GOP.gov.
15. Brian Montopoli, "Republicans Attack Size of House Health Care Bill," *CBSNews*, October 30, 2009, http://www.cbsnews.com/8301-503544_162-5463699-503544.html (March 29, 2010). Montopoli notes that "spending bills routinely exceed 1,000 pages, as do some other bills . . . Bush's 2007 budget bill," for example, "was 1,482 pages long."
16. Pence, GOP.gov.
17. Karen Tumulty, "Republicans Plot Their Health Care Attack Strategy," *Time*, November 23, 2009, <http://www.time.com/time/politics/article/0,8599,1942128,00.html> (March 29, 2010).
18. Mara Liasson, "GOP Uses Mammogram Study to Attack Health Bill," *NPR*, November 19 2009, <http://www.npr.org/templates/story/story.php?storyId=120562882> (March 29, 2010).
19. *Ibid.*
20. Sharon Begley, "The Five Biggest Lies in the Health Care Debate," *Newsweek*, August 29, 2009, <http://www.newsweek.com/id/214254> (April 30, 2010). Republican Betsy McCaughy, former lieutenant governor of New York, is quoted here. She first expressed this on a radio show. McCaughy's political career was catapulted by her 1994 critique of the Clintons' proposed health care reforms.
21. Jim Rutenberg and Jackie Calmes, "Rumor Dogging Health Care Reform Has Mainstream Roots; Conservative Journals Initiated Insinuations that Led to 'Death Panel' Talk," *International Herald Tribune*, August 15, 2009, in LexisNexis [database online] (March 29, 2010).
22. Begley.
23. *Ibid.*
24. Ashley Southall, "Order in the House, Please," *New York Times Prescriptions Blog*, March 23, 2010, <http://prescriptions.blogs.nytimes.com/2010/03/23/order-in-the-house-please/> (March 29, 2010).
25. Dan Gilgoff, "Abortion Debate Could Make or Break Health Care Reform," *US News*, September 14 2009, <http://www.usnews.com/articles/news/religion/2009/09/14/abortion-debate-could-make-or-break-healthcare-reform.html?PageNr=2> (May 2, 2010).
26. As it turned out, the United States Conference of Catholic Bishops remained opposed to the bill that was passed, while a broad coalition of nuns supported it. See Mitchell Landsberg, "Nuns in U.S. Back Healthcare Bill Despite Catholic Bishops' Opposition," *Los Angeles Times*, March 18, 2010, <http://articles.latimes.com/2010/mar/18/nation/la-na-healthcare-nuns18-2010mar18> (May 2, 2010).
27. A discourse analysis attends to the fact that meaning-making relies on the articulation of one thing *instead of another*. The health care debate brought forward a multitude of reasons in favor of health care, most of which were not articulated into the emerging discursive formation. Those selected were likely projected to have the greatest resonance and impact, and therefore to have the greatest potential to increase the administration's political power.
28. Sheryl Gay Stolberg and David M. Herszenhorn, "Two Sides Take Health Care Debate Outside Washington," *New York Times*, August 3, 2009, <http://www.nytimes.com/2009/08/03/health/policy/03healthcare.html> (May 2, 2010).
29. Strictly speaking, it was not "the Democrats" who led this effort, but the Obama administration and a handful of Congressional Democrats (Pelosi, Waxman, *inter alia*).
30. Of course, Obama is not the first Democrat to implement this tactic; many have noted his administration's similarities to Clinton's, both in staff and strategy.
31. Rutenberg and Calmes.
32. Barack Obama, "Obama at House Republican Retreat in Baltimore," transcript, *Huffington Post*, January 29 2010, <http://>

www.huffingtonpost.com/2010/01/29/transcript-of-president-o_n_442423.html (May 4, 2010).

33. While this might be interpreted as “one step back” to the Administration’s “two steps forward” in hegemonizing the terms of the debate, it need not be. Some analysts speculated that the President was not, in fact, trying to reason with the Right, but to expose their dearth of ideas for reform and their unwillingness to cooperate in a matter that has direct bearing on something conservatives claim to hold dear: fiscal responsibility.
34. Paul Krugman, “Comment & Debate: Guided by Spite: Venom from Republicans is Familiar, but This a New Low—and it’s a Clue to America’s Core Problems,” *The Guardian (London)*, October 6, 2009, in LexisNexis [database online] (March 29, 2010).
35. *Ibid.*

BOOK REVIEWS

Emperor of All Maladies: A Biography of Cancer

Siddhartha Mukherjee (HarperCollins, 2010). 592 pp.

Reviewed by Lauren C. Milner
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Introduction

Cancer has consumed Siddhartha Mukherjee for his entire professional life, as evidenced by the oncologist’s first book, *The Emperor of All Maladies (EoAM)*. Extensively researched and masterfully written, *EoAM* is highly ambitious “history” of cancer, spanning 4,000 years and chronicling many of the scientific, clinical, political, and personal narratives that have shaped our understanding of this elusive disease. However, an impartial history this is not: *EoAM* is a history with a message, more a historical argument than a historical account. Mukherjee acknowledges this himself with the statement that his “ultimate aim is to raise a question beyond biography” to the possibility of curing cancer, once and for all.

To argue towards the possibility of a cure, Mukherjee reinforces a classic metaphor, but adds a biological twist: in *EoAM*, cancer is portrayed as both our greatest enemy and our closest counterpart, “a distorted version of our normal selves.” *EoAM* documents the history of cancer primarily as an enduring war with battles on multiple fronts: professional battles of researchers and clinicians struggling to understand and define cancer, political battles of benefactors and advocates to make cancer a top priority in American health care, and personal battles of patients and their doctors to conquer the disease. War imagery abounds in *EoAM*, but Mukherjee is equally diligent in emphasizing the biological similarities between humans and cancer, as well as the many parallels between the evolution of modern disease and modern society. Ultimately, *EoAM* posits that the key to winning our war on cancer will require us to look inward, to our own cellular processes and fundamental flaws. Time will tell if Mukherjee is correct in his predictions about the future of our battle with cancer, but his message is worth consideration.

The Medical Battle

Like most medical histories, *EoAM* traces the history of cancer primarily through scientific and medical discoveries (and

discoverers) linked to the disease. Accordingly, the earliest history of cancer is defined much more by what is unknown than what is known about the disease. Cancer is present but sparse in archeological and historical records, a peculiar and incurable disease described as far back as the Egyptians (~2625 BC), but first systematically studied by Galen, a Greek physician who correctly identified cancer as a systematic (rather than localized) disease state, positing that cancer resulted from an internal overbalance of “black bile.” According to *EoAM*, cancer remained on the fringe of medicine for many years, growing as a threat in direct proportion to the success of medical research to overcome acute and infectious diseases, thereby increasing the average lifespan and general health of the human species. In short, cancer’s success is a reflection of our success: the first of many enduring themes encased within the book.

Following this introduction, *EoAM* dives into a lively and vivid narration of the true “beginning” of our war against cancer. Focusing primarily on leukemia and breast cancer, *EoAM* highlights the research histories and clinical outcomes of the three primary treatments for cancer: surgery, radiation, and chemotherapy. *EoAM* tracks the history of each treatment through its pioneers, those individuals possessing both unbridled ambitions and personal idiosyncrasies that keep readers tied into the otherwise serpentine path inevitably winding between basic science discoveries and their clinical applications. There is William Stewart Halstead, a nineteenth-century surgeon with a flair for the dramatic (he once performed surgery on his mother in their kitchen) who effectively illustrates the aggressive and reckless measures taken by surgeons in their first attacks on cancer. There is Emile Grubb, a “flamboyant, adventurous and fiercely innovative” medical student at the University of Chicago who first used x-rays to treat cancer and subsequently died from multiple forms of cancer caused by his experiments with radiation. There is Sidney Farber, a pediatric pathologist who championed the treatment of cancer through chemistry (i.e., chemotherapy) and helped to launch a campaign that transformed cancer from a biological enemy into political juggernaut whose influence continues today (see below).

These and many other researchers/clinicians who advanced cancer research/treatments in the past century are interwoven with basic biological descriptions of cancer’s various properties, as well as vignettes from Mukherjee’s own experiences as an oncological fellow at the Dana-Farber Cancer Institute at Harvard (including the narratives of many of his patients). The effect of this narrative style is both captivating and chaotic: I found myself to be completely engrossed in the narratives while simultaneously struggling to keep the facts in order. However, *EoAM* is successful in conveying the tumultuous history of cancer research, the incredible successes and failures that often come to define our history with complex diseases. These narratives and narrative style continue as *EoAM* expands cancer beyond the clinical realm into the political and social realm of the last half of the century.

The Political Battle

As *EoAM* moves into the 1950s, cancer makes a dramatic move beyond the research laboratories and medical clinics into the center of the public eye and, ultimately, to the floor of Congress. Here, *EoAM* focuses readers’ attention squarely on Sidney Farber and his outspoken partner in cancer advocacy, the socialite Mary Lasker. Through their creation of the American Cancer Society (ACS), Farber and Lasker staged a full-scale assault on cancer through large-scale fundraisers and advertising campaigns to find a “cure” and gain solid victory over cancer. ACS quickly became a powerful lobbying machine, demanding “goal-driven” research in place of what they believed to be the self-indulgent and academic research performed in the

basic science at the time. The campaign was in many ways successful, culminating in the National Cancer Act in 1971, widely regarded as the official beginning of the “war” on cancer. However, Farber and Lasker considered the Act inadequate to their cause, and withdrew from the cancer campaign as a result.

Mukherjee is openly critical of the approach of the “Laskerites” (his moniker) campaign because it transferred the power to direct research trajectories out of the hands of researchers and into the hands of “men of action” (e.g., lawyers, business executives). *EoAM* is also critical of the singular focus of the cancer campaign, which accompanied a period of cancer research characterized by disputes and general disarray (*EoAM* notes that the “War on Cancer seemed, at times, to have devolved into a war *within* cancer.”). By simplifying cancer to a singularity (“one cause, one cure”), *EoAM* suggests that the cancer campaign ultimately hindered research progress from detracting focus away from basic research and giving the public expectations for a cure that was not on the horizon.

Interestingly, the same recriminations are not applied to *EoAM*’s account of two other successful cancer advocacy campaigns, breast cancer and lung cancer, presumably because their aim was prevention and early intervention over cure. Like the “Laskerites,” both breast and lung cancer campaigns were catalyzed by large-scale campaigns and wars waged in public. For example, after clinical evidence overwhelmingly established smoking as a causal factor for lung cancer, a series of highly visible legal and political battles ensued, directly addressing the question of industry responsibility in lung cancer development. The anti-smoking campaign has ultimately succeeded in regulating certain aspects of the tobacco industry (such as advertising) and holding them legally accountable for their negative impact on public health. Similarly, campaigns promoting screening for cancer *before* it appears (“pre-cancer”) have moved screening from relative obscurity to routine health care for a handful of cancers (breast, ovarian, and prostate). Although these campaigns did not have to battle industry (like anti-smoking activists), they did create a sea change in medical spheres by promoting the concept of prevention over treatment. However, unlike the official “war” on cancer, these strategies are focused on individual types of cancer, which supports a more heterogeneous (and therefore more accurate) representation of the disease(s). Additionally, these campaigns promoted the prevention of health-risk behaviors and increased medical care instead of the aggressive drive for a “cure,” which is another likely reason they escape criticism in *EoAM*. The “success” of these campaigns as contrasted to the “failure” of the initial war on cancer also provides evidence for *EoAM*’s final message: that medicine’s ability to defeat cancer will not come from the development of a “cure,” but from the growing knowledge of human genetic, cellular, and behavioral processes. In short *EoAM* predicts that we will cure cancer from the inside out.

The Inner Battle (or the future of our war on cancer)

Despite the political success of cancer campaigning, the past forty years have seen comparatively little progress in effectively treating or curing the disease. Indeed, the aggressive and toxic approaches used by surgeons and oncologists hoping to cure cancer (or at least extend lives) often result in poor outcomes, including high recurrences and intolerable side effects for patients. As mentioned above, *EoAM* is also highly critical of the generalization and politicization of cancer, a transformation that it repeatedly cites as premature. In this message, *EoAM* is explicit: to date, our “war on cancer” has failed.

EoAM attributes this failure to a fundamental flaw of our overall research strategy: the drive for cure over cause. *EoAM* posits that effective treatments (and the possibility

of cures) can only be discovered through a much more comprehensive understanding of basic cellular mechanisms in cancer, mechanisms that are also inherent to our own cellular processes. In this way, *EoAM* offers its final (and most hopeful message): that the renewed focus in the basic cellular processes (especially genetics) of ourselves will ultimately lead to our victory over cancer. To prove this point, *EoAM* outlines early successes in treating cancer through a better understanding of the human endocrine system. For example, *EoAM* traces early discoveries linking breast cancer and estrogen production to the development of tamoxifen, an estrogen receptor antagonist and popular breast cancer therapy. However, the bulk of *EoAM*’s argument lies in the potential of genetic knowledge to treat cancer by tracking (in much detail) early advances in genetic research (from chromosome identification to measurements of heritability) and the early theories of cancer that arose from these discoveries (that cancer was caused through gene mutations in normally functioning cells). According to *EoAM*, understanding this basic biology is the path through which we can find effective treatments, and our shift in research focus back to basic science will result in our victory over cancer.

This is a seductive theory, and well supported by the detailed descriptions of cancer genetics research provided in *EoAM*. However, given the extraordinary successes (and subsequent failures) in the history of cancer research as outlined in the earlier half of the book, I remain unconvinced of an imminent victory. It certainly seems as though *EoAM* is pointing its audience towards the future of cancer (and many other complex and chronic diseases) by highlighting the promise of genetic medicine. However, *EoAM* itself provides the foundation for my skepticism: namely, if the history of cancer is delineated mainly by misguided advocacy and researcher hubris, what makes the genetic approach (or our current social climate) so different it will succeed where so many other approaches have failed? Despite *EoAM*’s thorough and reasonable arguments, it cannot predict the future. Therefore, we end the book wondering if the genetic revolution in medicine will remain the conclusion of *EoAM*, or an additional chapter to be included in the endless narrative of our war with cancer.

General Critiques and Conclusions

EoAM is an engrossing read, but accessible only to an audience highly educated in science and medicine. Although this may not present a critique in and of itself, it does limit the scope of the book to those who are already familiar with many of the social and research events that comprise much of the book. In this way, the message of *EoAM* may be lost to a broader audience, effectively preaching to the choir of the medical and scientific research community.

Another common critique of *EoAM* is that it verges on being discursive,¹⁻² a justified criticism in light of the numerous narratives, the constant movement back and forth through cancer’s history, and the construction of multiple complex themes (e.g., co-evolution of illness and society, the norms and values of the medical research community, etc.) provide a fractured progression of cancer’s history and can easily overwhelm readers. This multiplicity can also be frustrating, as a whole picture of cancer is never quite achieved, each chapter reminiscent of a blind man touching a different part of the elephant. The nature of *EoAM*’s approach may ultimately be the most accurate portrayal of cancer, with its complexities of etiology, appearance, and social history. However, *EoAM* also presents historical distractions (the history of tuberculosis, physical chemistry’s birth in the textile industry of England) that periodically lead *EoAM*’s audience far astray of the book’s main arguments. It is entirely possible to stay on track in *EoAM*, but the onus is on the reader to remain focused.

Despite these drawbacks, *EoAM* is an engaging attempt at providing a meaningful description of complex disease to audiences outside of the cancer research community. It is an eloquent and a compelling (if incomplete) story about our complicated history and uncertain future with cancer. Perhaps more important, *EoAM* provides a glimpse into complex interactions among biology, medicine, and politics when waging a war against disease, especially a disease whose power lies in its similarity to those it consumes. Whether or not you agree with Mukherjee's predictions of the victor in our war with cancer, his artful storytelling and insightful musings make *EoAM* an outstanding account of an enduring figure in biomedical history.

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Alan Wertheimer's Rethinking the Ethics of Clinical Research: Widening the Lens

Alan Wertheimer (Oxford, 2011). 356 pp.

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Alan Wertheimer's *Rethinking the Ethics of Clinical Research: Widening the Lens* is a well-argued and thorough discussion of perennially challenging issues in clinical research ethics. Wertheimer's prose is articulate and very occasionally humorous, although he always treats the topics under discussion with appropriate gravity. Wertheimer presents arguments so clearly that they can be formalized with numbered premises and conclusions—a boon both for bioethics scholars and those who aspire to teach bioethics in a systematic fashion. His work is a model of analytic research ethics, which is not a surprise, given Wertheimer's prior life as a professor of political philosophy before taking a post as a senior research scholar in the Department of Bioethics at the National Institutes of Health.

Wertheimer does not aspire to conquer the whole of research ethics. His aim is to go deep, not broad, by arguing extensively and persuasively for a limited number of controversial positions. For example, he argues in one chapter that we should not shy away from paying research participants more money. Wertheimer believes Institutional Review Boards (IRBs) that restrict payments to subjects fail to respect subjects' perspectives. Research subjects may find payment directly beneficial, in contrast to current IRB practice that financial compensation cannot count as a direct benefit of research. It is a moral failure for IRBs to not take into consideration the perspective of potential research subjects when assessing a research protocol. Some believe that paying a research subject automatically compromises the subject's autonomy, in particular the subject's ability to make a voluntary choice. And yet, we consistently pay people to do things that they wouldn't otherwise do, with limited ethical compunction. Wertheimer also believes that compensation may be only one motive among many for which an individual performs an action, so why should we think that the financial motive excludes an altruistic motive? Additionally, he argues, we allow persons to be compensated more highly for activities that involve greater assumption of risk. So why not pay research subjects more, in light of their willingness to take on substantial risks? The response is that unlike other high-risk professions, research is a special sort of good, in which the subject is a "passive target" or "locus of risk." Wertheimer responds that the distinction between active

and passive employment is neither clear nor robust enough to carry the argument. Wertheimer objects to claims concerning the possible degradation, incommensurability, or perversely economic views of individual interests, all of which are inherent in claims that payment treats human beings as commodities. Objections to payment based on equality, exploitation, or justice are similarly dispatched.

In another chapter Wertheimer considers informed consent. What work does informed consent need to do in order for consent to render an action morally permissible? Unlike philosophers who claim that informed consent allows us to not violate a Kantian "not merely as a means principle," Wertheimer looks elsewhere for the value of consent. Wertheimer is a proponent of the "fair transaction" model of informed consent, in which consent morally transforms an exchange between two agents: "B's consent is morally transformative if B tokens consent or appears to token consent under conditions in which A has acted fairly towards B in obtaining B's consent." Traditional views of informed consent include Faden and Beauchamp's model, which stress voluntariness, information, and competence. Wertheimer rejects traditional models, as they may prevent agents who are less than fully autonomous from entering into beneficial relationships. One consequence of his view: informed consent does not need to be particularly *informed*. After all, there are many cases in which persons aren't particularly informed, but consent has occurred. People consent to real estate transactions, sexual involvement, and employment opportunities in which they don't know the full range of all possible risks, benefits, alternatives, and costs, and yet consent is not unfairly compromised. Wertheimer makes these points by presenting long lists of examples from many areas of life beyond research ethics. Here, Wertheimer lives up to his claim to "widen the lens," drawing lessons from myriad examples beyond research ethics, assuming that the lessons learned are equally applicable to the research enterprise.

In the final chapter Wertheimer considers the Interaction Principle (IP). The Interaction Principle is the claim that one can have obligations or moral reasons to provide super-contractual benefits to those with whom one engages in mutually beneficial and consensual transactions. For example, I may pay a babysitter to watch my child on Saturday night. Ours is a mutually beneficial and consensual relationship. While I pay the babysitter a generous wage, I also make clear that he is permitted to eat anything in the refrigerator. I don't do this to compensate for poor wages; the food is an additional benefit. But do I really have a greater moral reason to feed the babysitter—who already benefits from being paid by me—rather than somehow ensuring that the food goes to people who don't have the employment opportunity the babysitter does? The Interaction Principle suggests that having entered into a mutually beneficial and consensual relationship with the babysitter makes it reasonable that I might have further obligations, even though the babysitter benefits from our interaction in a way that others do not. In the realm of research ethics, IP is cited as a reason that researchers from developed countries who use persons from less-developed countries as research subjects might owe additional obligations to those subjects beyond any benefits that result from research participation. What of the persons in the less-developed country who aren't research subjects? The researchers owe them nothing at all, even as IP implies the research subjects should receive not only the benefits of serving as subjects, but that they might be owed even more.

Wertheimer rejects IP, which has significant impact on practical issues in research: Researchers aren't required to be responsive to the medical needs of the population they

happen to be studying; researchers aren't required to use existing standards of care when randomizing against treatment arms; researchers are not obligated to provide ancillary care to research subjects beyond the care utilized as part of the research protocol. His argument turns on an examination of two corollaries of IP. The first is a "nonworseness" claim: It cannot be morally worse for A to interact with B than not if the interaction or package deal is beneficial to B and if B consents to the interaction. To accept IP is to reject this claim. Second, he examines a "greater obligation" claim: Among the potential beneficiaries of A's actions or resources, A has greater obligations to provide super-contractual benefits to B than to others, even though B has already benefited from interaction with A, whereas others have not. If one accepts IP, one would probably also accept the greater obligation claim. This chapter is Wertheimer's most abstract, and the one which has the greatest implications for areas outside of research ethics, including social justice questions such as the use of third-world labor in sweatshops, or political theory. It is clear here that "widening the lens" cuts both ways: claims in research ethics are made clearer by an examination of other aspects of ethics, other aspects of ethics may be illuminated by a rigorous examination of research ethics.

Which then raises one of the few shortcomings of Wertheimer's book. With whom does the burden of proof lie when we consider whether research ethics is, or is not unique,

or whether the moral principles which hold in other aspects of life are similarly applicable in clinical research ethics? After all, many assume that research ethics *is* unique—Wertheimer cites them extensively. Assume that one party claims that X and Y are fundamentally similar, whereas another party holds that X and Y are fundamentally different. Whose arguments must be stronger? Given that historically people have held that in this case X (the ethics of clinical research) and Y (ethical claims in other realms) are different, it might not be too much to ask that Wertheimer engage the question more thoroughly.

Wertheimer begins his first substantive chapter, after the introduction, with the question "Is the current research regulatory framework fundamentally paternalistic?" He argues that the current regulatory practices are an example of group soft paternalism. Both the studies that are available for enrollment, and the terms under which participants may enroll, are paternalistically controlled by IRBs. Wertheimer holds that neither nonmaleficence, nor a principle of nonexploitation, offers a sufficient justification for this paternalistic regulatory system. The argument assumes that principles like nonmaleficence or nonexploitation are easily transferable from other ethical realms—such as therapeutic ethics or political philosophy—to research ethics. Are these principles so easily transferable, or is there something unique about research ethics that justifies this paternalism? And if research is unique, might that not be such a bad thing? No—it might not be such a bad thing all.