

Chapter 10
Health and Other Reveries
Homo Curare, Homo Faber, and the
Realization of Care

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To endeavor to shape people and populations to conform to an “imagined future” in which the present ascendant values, understandings, and intentions are manifest . . . is not only eugenic but also an untenable enterprise.

—Rosemarie Garland-Thomson¹

“It would be naïve to seek solidity in a heaven of ideas or in a *ground (fond)* of meaning—[. . .] the very idea of objective knowledge and . . . the idea of an object that informs itself and knows itself are, as much as any other ideas, and more than any other, supported by our reveries.”

—Maurice Merleau-Ponty²

Introduction

Modern scientific methods have allowed humans to significantly extend their average lifespan, create life under circumstances previously thought

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1 impossible, and maintain life after both environmental and genetic
 2 events that in centuries past would have meant immediate or inevitable
 3 death.³ Whether one looks to the policies of the NIH, UN, or Gates
 4 Foundation, this wealth of scientific knowledge about the human body
 5 has transformed how we think about individual humans as well as the
 6 fundamental framework and goals of their sociopolitical existence. Gov-
 7 ernments govern, communities coalesce, and individuals choose by and
 8 in parameters set by the value of health and the many private and public
 9 entities that produce its power, knowledge, and guidance. Yet, modern
 10 scientific methods and their manifold effects have also put within reach
 11 the total annihilation of our species and set into motion global processes
 12 that will powerfully curtail, if not hasten the end of, human life on Earth.
 13 Initially, this potential extinction will likely come through the widescale
 14 death and suffering of historically marginalized groups and the economically
 15 disadvantaged.⁴ Both at the level of knowing and of praxis, the methods
 16 and modes that underwrite the rise of the biopolitical—and, increasingly,
 17 the infopolitical—are the very methods and modes that have underwritten
 18 processes of global injustice the scale of which are unparalleled across
 19 recorded history.⁵ Where, precisely, does *health* fit in this history?

20 Socially and politically, modern conceptions of health function
 21 as a stratagem or gambit. They assume a certain naiveté regarding the
 22 mortal necessity and curious transitions of aging, the social construction
 23 of normality, and the biological ambiguity of typicality—of the *typos*, the
 24 kind. This naiveté is profoundly productive. The fear of death and the
 25 changes it occasions are best tamed by never rising to the level of a fear:
 26 *I'm not afraid of dying; I just want to live life to the fullest.* The desire to
 27 be normal, to not be a *misfit*, is best tamed by being framed as a desire
 28 for flourishing: *I'm not against being different; I just want things to go more*
 29 *easily as I pursue my goals.*⁶ The instinct to categorize things absolutely is
 30 best tamed by an impassioned fidelity to scientific method, the density
 31 of fact, and the gravity of the mean: *I'm not saying there aren't variations;*
 32 *I just want you to know how evolution has structured things.* Each of these
 33 strategies contribute in fundamental ways to the positive production of
 34 health, a production that garners and leverages untold amounts of capital
 35 and, far too often, functions to cover over a litany of historic and con-
 36 temporary injustices baked into the fabric of each society it touches. The
 37 truism that “everyone wants to be healthy” is superseded in rank only by
 38 the assumption that there is such a thing as health—that health is an
 39 objective fact of the world by which we can produce objective knowledge
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about morbidity and mortality, functioning and flourishing, and forms of
life. Is health, then, a *reverie*?

In the epigraph above from *The Visible and the Invisible*, Merleau-Ponty claims that “the very idea of objective knowledge [is] supported by our reveries.”⁷ My aim in this chapter is to interrogate this claim with respect to the phenomenon of health. In section one and as a case study for the analysis to follow, I look at a contemporary, highly specific site of health screening: return of results of incidental variants or variants of unknown significance with respect to the use of genetic and genomic screening technologies (GSTs) in newborn and pediatric contexts. These screenings, undergirded by decades of basic, applied, and transitional work in genomic medical sciences as a whole, produce situations wherein parents might face knowing, or face potentially knowing, the health fate of their own children—a fate that could include early and inevitable death. Drawing on a range of Merleau-Ponty’s texts, but with a special focus on his Collège de France lectures on the concept of nature, I show how this scene of care reveals a tension between the macro and the micro, between medical research and practice as a science of the general and the patient’s interest in medical care as an art of treating the individual.

In section two, I further develop this concern by arguing that genomic medical sciences reveal an even more fundamental tension between two distinct ways of conceiving of the human: *homo faber*, the human understood as controller of fate through the creation and use of tools, versus what I term *homo curare*, the human understood as conspiring with fate through the guidance and practice of care. Each of these conceptions lead to distinct interpretations of the proper role and balance between the macro and the micro. I argue that by looking to Merleau-Ponty’s concept of the flesh it becomes clear that *homo faber* and *homo curare* are but two modalities of the relationship between fleshly beings like us and the concept of health.

In the final section, I examine the aforementioned arguments in the context of larger issues of social justice. With respect to the studies that I examine and given the demographics of those with access to technologies like GSTs, I suggest that under the aegis of *homo faber*, health functions as a reverie that creates and upholds white, cishet, able-bodied, settler colonialist, upper-middle-class privilege. This, then, is “health” not as a harmless reverie, but a dangerous reverie particularly apt to contribute to and maintain injustice in both theory and practice. It is only by better balancing *homo faber* and *homo curare*, the human as *maker* and the

1 human as *carer*, that the idea of health will transform from a dangerous
2 reverie into a more just reality.

3 An initial caveat is in order concerning how this piece fits in relation
4 to the large body of scholarship on Merleau-Ponty. Research engaging
5 central figures in Continental/European philosophy typically takes two
6 forms today. There is figure scholarship, which works out philosophical
7 problems directly through or within the oeuvre of the thinker or thinkers
8 in question. There is also problem-based scholarship, which uses the insights
9 of a thinker or thinkers to address and gain understanding concerning a
10 problem. This chapter is an instance of the latter. Both approaches strike
11 me as valuable, for different though at times overlapping purposes. Still, it
12 is worth noting that a problem-based use of continental figures is arguably
13 more common in the social sciences than it is in the humanities (just
14 consider the wide range of use of figures like Michel Foucault, one of
15 the more cited figures in the twentieth century as a whole). One reason
16 for this is that the social sciences are, at least typically, oriented toward
17 building knowledge about various sorts of social phenomena as opposed to
18 learning more about a particular thinker. I adopt a problem-first method
19 here because while working upon ethical, legal, and social issues related to
20 genomics, I found myself turning again and again to Merleau-Ponty for
21 insights concerning the debates at play—whether with respect to return
22 of results of secondary findings or the psychosocial impact of genomic
23 knowledge upon people more generally. In short, it was by turning to
24 Merleau-Ponty for discernment and understanding of pressing concrete
25 problems that this project came to fruition, and this chapter engages
26 Merleau-Ponty in that admittedly applied spirit.

27 28 29 Would You Like to Know When Your Child Will Die?

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31 *Your young child is exhibiting unusual physiological or behavioral*
32 *symptoms. You have anguished over their meaning, maybe for*
33 *months or even years—anguished over what may or may not be*
34 *the case. At the suggestion of your medical provider, you agree to*
35 *whole genome sequencing. You do so because you think it is the best*
36 *way, and perhaps also the last way, to figure out what is going on*
37 *in order for you to know how to care for your child. Not another's*
38 *child or children in general, but your child. Genomic information*
39 *will help one do this.*
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The assumption concerning the helpfulness of genomic information in this vignette in fact runs counter to the methodological milieu of modern medical science as well as modern medical care. The ultimate focus of the primary institutions of modern medicine turns not on the person as unique microcosm—one laden with a singular history, personal, biological, genomic, and the like, and with unique cares, traumas, fears, desires, and plans—but on the person as macrocosm, as a particular instance of homo sapiens or of some specific population of homo sapiens.⁸ In *Nicomachean Ethics*, Aristotle writes, “for what the doctor appears to consider is not even health, but human health, and presumably the health of this human being even more, since he treats one particular patient at a time.”⁹ In this terse formulation, Aristotle lays out the complex relationship between the practice of individualized care, of *singular, micro-level treatment*, and the reflective, knowledge-building processes concerning human health, of *general, macro-level* considerations. Although there is a singular patient before a clinician, the knowledge brought to bear on that patient is knowledge ultimately developed in and derived from the vast body of modern scientific knowledge about humans and about patients—knowledge that has grown exponentially in recent decades. Yet, as Aristotle contends, the end of medical care is nevertheless presumed to be the care of the specific patient a clinician is treating. As calls for the import of narrative medicine as well as values-based practice makes clear, focus on the patient as an individual is not today the norm.¹⁰ At the heart of modern medicine, at least, lies a tension between the micro and the macro.

Merleau-Ponty, in the context of a larger critique of a statistical approach to evolution, puts a finer point on the issue, writing “in all the sciences, there is a distinction of the micro and the macro, beyond the principle of causality . . . the schema are everywhere the same, absorbing the ‘historical given.’ The macroscopic facts of evolution do not bring out more of this analysis than does the aerial photo of the electronic microscope.”¹¹ A few lines later, he argues, “geneticists study evolution from the point of view of *Homo faber*.”¹² Within Merleau-Ponty’s view, genetics (and what would later be called genomics) is a macro-level study of the structures of natural development carried out under the auspices of being able to change human fates; genomics plays out on one side of the medical tension Aristotle describes.

Laying the groundwork for later historians and critics of genetic and genomic sciences such as Lily E. Kay, Troy Duster, Nathaniel Comfort, and Colin Koopman, Merleau-Ponty understands contemporary

1 genomics as an instance of third-person, modern scientific knowledge that
2 is predicated upon the assumption that the human can, through what
3 is ultimately macroscopic knowledge about the human organism, build
4 tools to control its own fate, including at the level of the microscopic.
5 Genomics, on this view, is a project of and for homo faber: the human
6 understood as master of its own fate. This places the question at hand in
7 sharper terms: will genomic health information, operating fundamentally
8 as it does at a macro level, help you know how to care for *your* child?

9 To answer that question, consider the following example. Since
10 2010, the American College of Medical Genetics has supported chro-
11 mosomal microarray as a first-tier test for individuals with several types
12 of suspected genetic diseases.¹³ These screenings can determine whether
13 or not someone has a copy-number-variant (CNV), and here is the sort
14 of information a parent, presented with the option or suggestion to agree
15 to such a test for their child, might encounter:

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17 CNVs are a type of structural variant involving alterations in
18 the number of copies of specific regions of DNA, which can
19 either be deleted or duplicated. These chromosomal deletions
20 and duplications involve fairly large stretches of DNA (that
21 is, thousands of nucleotides [>1 kb], which may span many
22 different genes) but can range considerably in size as well as
23 prevalence. As is the case for other types of genetic mutations,
24 some CNVs are inherited whereas others spontaneously arise
25 de novo . . . There are several well-characterized rare develop-
26 mental phenotypes caused by CNVs of known pathogenicity,
27 such as Velocardiofacial, Prader-Willi, and Smith-Magenis
28 syndromes. Although the role of most CNVs is far less clear,
29 there is now growing evidence that the genetic architecture
30 of more common psychiatric and neurodevelopmental con-
31 ditions includes different types of both common and rare
32 genetic variation. An increased burden of rare CNVs has
33 been observed and replicated in several conditions. These
34 include autism spectrum disorder (ASD), attention-deficit/
35 hyperactivity disorder (ADHD), and intellectual disability
36 (ID), as well as schizophrenia. CNVs also contribute to risk
37 of idiopathic epilepsy.¹⁴

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39 Werner-Lin and colleagues detail the case of a mother who under-
40 went chromosomal microarray screening. Her baby tested positive for a

copy-number-variant with a highly variable phenotype. The mother reports that her provider reactions ran the gamut from: “Doom and gloom” to “this baby’s perfectly fine, why are they putting you through this?” As her daughter reached six months, she said: “I’m constantly questioning ‘is this because of her disorder?’ For example, she’s a really bad sleeper so for the longest time I thought ‘wow, is this her deletion or is it just that she’s five months old and she sucks at sleeping like most babies?’”¹⁵ Another parent said:

Once or twice it’s crept into my head where I’ve been like, “what if this microarray result . . . like there’s something wrong with her and we don’t know and one day she just has SIDS [sudden infant death syndrome] and stops breathing.” She’s got such a strangely mellow temperament, so I think, “is there something wrong with her that she’s just so lovely”—which makes no sense.¹⁶

Geneticists study evolution from the point of view of homo faber, yet parents, these studies suggest, seek out and interpret genomic information from the point of view of homo curare. I coin this term to refer to the human understood from the point of view of a being oriented and defined by care, i.e., a being instituted and constituted through relations of concern.¹⁷ These parents are not interpreting genetic information qua homo faber, but qua homo curare. That is to say, these parents report micro-level concerns—specifically ones concerning the possibility of their child becoming “abnormal,” which, tellingly, always acts in these studies as a synonym for “disabled.”¹⁸ They struggle to reconcile macro, genomic information understood from the view of homo faber with its micro, lived meaning understood from the view of homo curare.

By characterizing the issues and scenes at hand in this way, I do not merely aim to invoke the architectonic role of care (*Sorge*) in Heidegger’s *Being and Time*. As important as that analysis is, it offers little understanding of the role of embodiment for the institution, determination, and provision of care. Instead, I primarily aim to highlight the way that our reasons, actions, judgments, perceptions, and cognitions are all shaped by *Einfühlung*, which is to say, shaped by a *fleshy* body that feels above and beyond any of those “feelings” that rise to the level of consciousness and thereby earn the name. “Before trying,” Merleau-Ponty writes, “we notice that the body as corporal schema, the esthesiological body, the flesh (*le corps, comme schéma corporel, le corps esthésiologique, la chair*) have

1 already given us the *Einfühlung* [typically translated as “empathy”] of the
 2 body with perceived being (*l'être perçu*) and with other bodies. That is,
 3 the body as the power (*pouvoir*) of *Einfühlung* is already desire, libido,
 4 projection-introjection, identification.”¹⁹ The body, for Merleau-Ponty, is
 5 always already a scene of *em-pathy* understood in this expansive sense, a
 6 scene of what I understand in terms of and as defined by care. And the
 7 meaningfulness of bodily actions and bodily styles—from being a “really
 8 bad sleeper” as the first parent worries to having a “strangely mellow
 9 temperament” as the second parent worries—are interpreted in the light
 10 of enfleshed *Einfühlung*. In these cases that translates to a desire for nor-
 11 mality, the fear of “becoming disabled,” and the preemptive identification
 12 of their “true” child—the child they were supposed to have and/or the
 13 child who was supposed to develop, as “normal” and “healthy.”

14 To appreciate this point, a more careful discussion of the meaning
 15 of the flesh (*la chair*) is in order. For Merleau-Ponty, the flesh names
 16 that texture in and through which the body and world touch—the ori-
 17 gin point of all horizons in which things become possible phenomena
 18 of concern. He writes, “This magical relation, this pact between them
 19 [things] and me . . . this fold, this central cavity of the visible which is
 20 my vision, these two mirror arrangements of the seeing and the visible,
 21 the touching and the touched, form a close-bound system that I count
 22 on . . . the flesh (of the world or my own) is not contingency, chaos, but
 23 a *texture* that returns to itself and conforms to itself.”²⁰ To understand
 24 the flesh as a texture indicates that it neither exists in pure space (the
 25 geometer’s formulae cannot, e.g., render the “red shaggy carpet”), nor in
 26 pure time (there is no quantifiable time in which the run of one’s hand
 27 over the carpet “grasps” its shagginess, specific texture, or its redness). The
 28 flesh, in short, is that medium through which things become meaningful.²¹
 29 The flesh, one could say, is a turgid or tumescent concept, which is to
 30 say, part of what the concept picks out is precisely a conceptual excess
 31 beyond the binary couplings so easily birthed and latched onto by beings
 32 like us. The “really bad sleeper” and the “strangely mellow temperament”
 33 are not the results, potential or actual, of genomic differences. They are
 34 moments of apprehension of our fleshly being in the unending project
 35 to understand its meaningfulness.

36 Understood as flesh, the body is the ground of the possibilities of
 37 the human as *homo curare*, and it is so through a complex interaction
 38 of the body as the power (*pouvoir*) of *Einfühlung*, as a texture already
 39 shot through with specific desires, libidos, projection-introjections, and
 40

identifications. To be a fleshly being, then, just is to be a being defined
 by care. As I explain in more detail below, both *homo curare* and *homo*
faber are modalities of beings of flesh; both are responses to and ways
 in which such a form of existence is taken up as a project.

Homo Curare, Homo Faber, and Flesh

*You agree to whole genome sequencing, just as those parents did. You
 do so because you think it is the best way, and perhaps also the last
 way, to figure out what is going on in order for you to know how
 to care for your child. However, during the appointment to receive
 the results of this test, you are told the sequencing revealed a piece
 of information about your child's future that has nothing to do with
 either your present concerns or that of your doctors. Hence the name
 incidental or secondary variants. Among other things, these findings
 could suggest that your child will succumb to Huntington's disease,
 a fatal genetic disorder that causes the progressive breakdown of
 nerve cells in the brain. "Symptoms usually appear between the ages
 of 30 to 50 and worsen over a 10- to 25-year period. Ultimately,
 someone with Huntington's succumbs to pneumonia, heart failure,
 or other complications" due to the progression of the disease.²² It
 is possible, however, that the variants portend a condition far less
 severe, or maybe they end up meaning nothing at all.*

*But your medical provider can't explain any details until you
 first agree to hear the information. And even if the variant does
 suggest something as momentous as Huntington's, the data could be
 wrong or ambiguous. Because, it always bears repeating, these tests
 do not tell you what will happen. They do not and cannot predict
 the future with absolute certainty. Your genome does not, all on its
 own, fully decide your future. One's environment affects which genes
 are expressed over time, and also how they are expressed. Even in
 the case of monogenic diseases—diseases originating from a mutation
 in a single gene present on one or both chromosomes—the story and
 timeline of their phenotypic expression is complicated and diverse.*

*Even if genes did have this magical power, these tests can
 provide false positives. They are, of course, limited both to the
 current state of medical knowledge about genomics and also to the
 information sequencing and analysis on the computer science side,*

1 *which is to say, all the many technological devices and program-*
 2 *ming algorithms that make possible in the first place the sequencing*
 3 *and analysis of genomes on the way to their diagnostic-prognostic*
 4 *interpretation.*
 5

6 To address this situation, let us return to the tension discussed above
 7 between the micro and the macro. Merleau-Ponty continues, “there is a
 8 complementarity that forbids the simultaneous fixing on the micro and
 9 the macro.”²³ The term “complementarity” is here deployed in the sense
 10 used by physicists to describe how “the capacity of the wave and particle
 11 theories of light” are complementary insofar as they together “explain all
 12 phenomena of a certain type, although each separately accounts for only
 13 some of the phenomena.”²⁴ Complementarity, in this sense, does not
 14 suggest that one of two (or more) ways of understanding, perceiving,
 15 judging, or conceiving of a phenomenon is necessarily better or more
 16 accurate than another; it is only to say that (a) those ways are distinct
 17 in determinate respects, (b) it is only through bringing both explanatory
 18 modes together that one will end up with a more holistic understand-
 19 ing of the phenomenon in question, and (c) one cannot hold both ways
 20 together at the same time. Indeed, how would one bring together the
 21 explanatory modes at the macro-level of genomics with the micro-level
 22 of a singular life? How would one bring together information, knowl-
 23 edge, and understanding fashioned in the light of *homo faber* with that
 24 of *homo curare*?

25 The role of the flesh—and, thereby, the distinct modalities of *homo*
 26 *curare* and *homo faber*—is difficult to see on the dominant macro-level
 27 understanding of the meaning of genomics. David Morris, working to
 28 correct the dominant interpretation, writes:

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 30 [Genomic] information has standing as such only by virtue of
 31 ongoing and historical material and energetic dynamic flows
 32 that are part and parcel of what it takes to inherit genetic
 33 material and grow a body. These flows move through the
 34 medium of growing bodies in environments. We think the
 35 genetic information is there, right in and reducible to genetic
 36 material. But what we are really seeing when we (rightly) grasp
 37 genetic material as having an informative role is an effect of
 38 ongoing biochemical histories and dynamics washing through
 39 a body growing in this-here place.²⁵
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Although Morris does not use the language of the flesh at this point in his argument, I understand “a body growing in this-here place” as a gloss on that concept. A properly “enfleshed” understanding of genomics sees the way in which it neither presents us with definitive control over populations or individuals, nor does it tell us how to care. It is, instead, but one slice of ongoing and historical material and energetic dynamic flows—one slice of an organism understood in terms of what Merleau-Ponty calls an “envelopment-phenomenon”:

[The] organism is not only its local-instantaneous reality, neither for a proximal thinking, nor moreover another reality. It is the macroscopic “envelopment-phenomenon” [*phénomène-enveloppe*] that we do not engender from elements, that invests the local-instantaneity, that is not to be sought *behind*, but rather *between* the elements . . . instead of a science of the world by relations contemplated from the outside (relations of space, for example), the body is the measurement of the world [*le corps est le mesurant du monde*].²⁶

To say that the body—again, understood here as flesh—is the measurement of the world is to say that the meaningfulness of the world emerges against the horizon of our cares and our control. The tension of the micro and the macro is that span in which we measure our cares. The tension at play in the scenes of care analyzed above for parents seeking out genomic information is a tension between such measurement understood as a tool for control and such measurement understood as a tool for care. Our imbrication with the world, our fleshly being-in-the-world, is the stuff out of which and by which measurements like these can be taken.

Recall the central question at stake in GSTs: what does it mean, today, to care for one’s child—and not just their present, but as modern biomedical technologies increasingly promise, their future? More specifically, what does the twentieth-century project of genetics all the way from Watson and Crick’s (and Franklin’s) discovery of the double-helix to the contemporary promises of the Human Genome Project indicate about the evolution of the flesh? About the human as a being shot-through not merely with senses trained by the social and scientific, not merely causes and determinates, but also cares—the weight of an ever-unique texture that both conditions us and opens us up to what makes our condition *our own*? What does this evolution portend for the epistemic space and

1 intentional reach of our care for others, especially, in this case, intimate
 2 others? Concerning such questions, homo faber, just as homo curare,
 3 is condemned to uncertainty. Heeding Merleau-Ponty's concept of the
 4 flesh, the difference between homo faber and homo curare is, then, not
 5 one of kind, but degree. Cares borne in the body qua flesh already span
 6 the hermeneutic distance between homo faber and homo curare, for it
 7 is as flesh that the micro and the macro come together at the level of
 8 lived experience.²⁷

9 At this point, the following claim can be offered: the meaning-mak-
 10 ing relationship between homo faber and homo curare is one of modes
 11 of fleshly care. The human as creator of a world and of its fashioning
 12 is one modality of the human who explicitly measures the world in
 13 terms of its cares; cares that are always indexed to its institution and
 14 constitution as a fleshly, embodied being. Cares envelop all phenomena
 15 within one's world—that is, within the totality of meaningful relations
 16 of one's experience—and the meaningfulness of caring as well as any of
 17 our particular cares emerges out of the envelopment-phenomenon that
 18 is the flesh in its irreducible relationship with its environment. It is in
 19 this sense that care operates at the interstices of inside/outside, first- and
 20 third-person, micro and macro views. Care is determinate for meaning,
 21 for *sens*, by fundamentally mediating the phenomenality of phenomena.

24 Existential Homeostasis and Existential Support

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 26 While I have explained the relationship between homo faber and homo
 27 curare in some depth, I have not yet addressed the problem of how we
 28 care or how we conceive of care. It is through this question that the
 29 differences between homo faber and homo curare emerge at their stark-
 30 est. For homo faber, what is ultimately at stake in scenes of genetic and
 31 genomic sequencing technologies is *care conducted as control over fate*—a
 32 control fashioned through the creation and use of tools. For homo curare,
 33 what is ultimately at stake in scenes of genetic and genomic sequencing
 34 technologies is *care conducted as provisioning of support*—a control fashioned
 35 through working with others and community and acting upon the social
 36 conditions that make caring possible in the first place.

37 For homo faber, care conducted as control over fate aims at *existen-*
 38 *tial homeostasis*: the experience of feeling that the meaning of one's life
 39 will stay the same. Existential homeostasis is underwritten by a desire
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for normality; it is an experience of the continuity or trapping of ability 1
 relations and the linking of that experience with the meaning and main- 2
 tenance of health.²⁸ If that account is right, then health as a reverie of 3
 homo faber is a project to extend the trap of fluctuation that constitutes 4
 the organism to the experiential field of that organism. Health becomes 5
 a forgetting of both fluctuation and the traps that hold it. That is to say, 6
 there is a way in which the desire to establish normality—in this sense of 7
 the trapping of what is taken to be “one’s own” abilities as the only way 8
 to establish health—is an act taken in defiance of both the life course 9
 and bodily difference. As long as human cares are shaped by a demand 10
 for health as longevity and health as normality, a fundamentally ableist 11
 demand, that vision of health will orient the measurement of the world. 12
 It will become a phenomenon through which the world is enveloped 13
 and, thus, against which it is measured. In this light and based upon the 14
 qualitative sociological work analyzed above that one can see why scenes 15
 of care driven primarily by homo faber are destructive, for this way of 16
 being-toward-health seeks not to create the conditions of support for the 17
 health of all, but instead to conduct control over the fate of solely one’s 18
 own, in this case, one’s own child. 19

For homo curare, care conducted as provisioning of support aims 20
 not merely for existential support, but social support: the provisioning of 21
 assistance for the care of those around one. Insofar as the orbit of concern 22
 of homo curare extends beyond oneself and one’s kin, social support is a 23
 project of justice. Scenes of care like those involving GSTs are not simply 24
 about the meaning of one’s child’s life but about the world in which one 25
 and one’s child lives. Homo curare is actively attuned to the ways in which 26
 one is always already in relation with others and with their wellbeing. 27
 The demand for health as individual longevity and health as normality, 28
 paradigmatic of homo faber, transforms into a demand for health for *all* 29
of us for homo curare. 30

To better appreciate the distinction between homo faber and homo 31
 curare, take another study of parental responses to receiving information 32
 from GSTs concerning their children. J.A. Anderson and colleagues 33
 write that 34

Of 83 invited, 23 parents from 18 families participated [in 36
 the study]. These parents supported WGS [a form of GSTs] 37
 as a diagnostic test, perceiving clear intrinsic and instrumental 38
 value. However, many parents were ambivalent about receiving 39

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1 SVs [secondary variants], conveying a sense of self-imposed
 2 obligation to take on the ‘weight’ of knowing [this informa-
 3 tion], however unpleasant.²⁹

4
 5 They found themselves in the thralls of duty, undergoing a deep norma-
 6 tive pull, to take on the weight of this knowledge. Would you take on
 7 this weight? After being told that there is secondary variant information,
 8 you, after much deliberation, decide to decline the information. Yet, if
 9 something happens down the road, how will you deal with knowing you
 10 might have mitigated it? If you accept it, won’t that information affect
 11 how you treat your child? When and in what way will you tell them?
 12 How old is old enough to learn you might suffer an early death or will
 13 soon be living with some kind of illness or disease? Fifteen? Twenty-one?
 14 Forty? There are no easy answers and no easy way out of this dilemma
 15 once you’re in it.³⁰

16 Anderson and colleagues suggest the term *inflicted oughts* to refer
 17 to the obligation to take on the weight of knowing secondary variant
 18 information. What does it mean to inflict an ought? To inflict a respon-
 19 sibility or duty as one would a wound? What is the relationship between
 20 control and care, between *homo faber* and *homo curare* offered here?
 21 Most imagine the knowledge provided by secondary variants of GSTs
 22 to be a good—a good even if the specific information they proffer por-
 23 tend something bad—a good we seek and simultaneously hate to find.
 24 Is it, though? Even if research concerning the psychosocial impacts of
 25 genomic testing found it to not cause empirically demonstrable harm,
 26 would that mean this information thereby contributes to individual or
 27 familial well-being or—just as, if not far more importantly—contributes
 28 to a more just and equitable society?³¹ What reveries are at play here?

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31 Justice and the Realization of Care

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33 If, for *homo faber*, care is conducted as control over fate, conducted as
 34 a desire for existential homeostasis, then the scenes of care and the use
 35 of GSTs discussed above turn on the conversion of the fear of death as
 36 linked to abnormality into a knowledge that allows one to regulate or
 37 control that fear, the course of one’s life, and the eventualities of one’s
 38 ability transitions and ultimate death—and/or, by extension, that of
 39 one’s loved ones. As Attic tragedy works to make clear, such knowledge

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always comes with a cost. And, as contemporary scholarship in critical theory, feminist theory, critical philosophy of race, disability studies, and queer theory, among multiple other fields, makes clear, such knowledge is also always a product of power—of one’s place, historical context, social position, and other elements. Knowledge such as this is haunted by epistemologies of ignorance.³²

For example, there are harrowing racial dimensions embedded in the value and interpretation of genomic knowledge. That a middle-class white couple—demographically those most likely to have access to and use such genetic screening technologies—would be aghast at the thought that their child might die at age thirty-five of, say, Huntington’s disease, is in part an existential effect of white privilege.³³ It evidences an ignorance that too many Black or Latinx parents, for example, must face this prospect as an everyday social-political reality rather than as a rare genetic circumstance. It must be faced by such parents due to factors ranging from police violence, to hate crimes, to inequalities of health, housing, employment, and other systemic problems perpetuated at state and federal levels across the United States—as well as many other parts of the globe, to invoke the global colonial and imperial conditions supporting such practices.³⁴

With respect to the experience, interpretation, and ensuing psychosocial and existential impacts of receiving results from pediatric genome sequencing, what is ultimately at stake here for homo faber is the desire to establish that the meaning of one’s child’s life will stay the same. This involves a core, operative assumption that this meaning will include a *long, able-bodied* life indexed to white, settler colonial privilege. Within these cases, at least, homo faber figures concern over controlling the fate and facts of one’s child’s life and death as a question of the meaning of one’s child’s life as a particular, hegemonic figure of the *normal*. And normality is always already shot through with problematic frameworks based on race, gender, sexuality, nationality, ethnicity, class, and so on.

In *The Phenomenology of Perception*, Merleau-Ponty writes, “I can only encompass a certain duration of my life by once again unfolding it according to its own *tempo* . . . the ‘synthesis’ of time is a ‘transition synthesis’ and the movement of a life that unfolds, and the only way to actualize this life is to live it [*et il n’y a pas d’autre manière de l’effectuer que de vivre cette vie*]; time has no place, rather time carries itself along and launches itself forward.”³⁵ In order to function as a reverie, health for homo faber must act in ignorance of the very dimensions of living

1 it seeks to uphold. For example, it must ignore aging,³⁶ adaptation, and
 2 the profound necessity of ability transitions and their many bearings and
 3 sendoffs; it must focus on the micro at the expense of the macro—tak-
 4 ing the macro as having meaning only insofar as it affords the micro its
 5 desires; it must overlook and forget all the fluctuations, deprivations, and
 6 assaults on health that are not simply inevitable but which condition the
 7 possibility of life and any form of “health” within and along its course.
 8 And, ultimately, it must take on the form of a dogmatic idea that sup-
 9 presses *homo curare*. Finally, to function as a reverie, health for *homo*
 10 *faber* must occlude the fact that we are beings of flesh.

13 In Defense of Reveries of Egalitarian Health

15 The desire to know one’s own or one’s loved one’s future, I have argued, is
 16 underwritten by two foundational ways in which we live in and as beings
 17 of flesh: *homo faber* and *homo curare*. I have argued that whereas *homo*
 18 *faber* leads to the desire for existential homeostasis, a feeling of surety
 19 that the meaning of one’s life will stay the same, *homo curare* leads to
 20 the desire for existential support, the provisioning of assistance for the
 21 care of those around one. Both *homo faber* and *homo curare* are integral
 22 modalities of fleshly beings like us. I have devoted a significant amount
 23 of the chapter to criticizing the dominance of *homo faber* because it is,
 24 regrettably, the default and dominant modality at play in these scenes of
 25 care. Insofar as *homo faber* is not balanced with *homo curare*, it creates
 26 a serious problem—especially if one keeps larger concerns of social justice
 27 and equitable health care in mind. On the other hand, the modality of
 28 *homo curare* is certainly problematic, morally and otherwise, insofar as
 29 it alone is dominant. A generalized care for all that fails to attend to
 30 particular others, including loved ones and close friends, is a failure of
 31 care and can lead to harms against individuals in all sorts of ways.³⁷ But
 32 that is not the chief problem genomic medical sciences and what I have
 33 discussed in terms of the reverie of modern health presents us with; it
 34 is instead the dominance and hegemony of *homo faber*.

35 I have further suggested that insofar as modern ideas of health are
 36 based solely or unevenly on a conception of the human as *homo faber*,
 37 health functions not simply as any reverie but as a dangerous reverie
 38 that maintains unjust and inequitable systems of care. Health is not and
 39 never has been individual. It is a question of the reach of one’s entire
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community and society—including the reach of oneself into and with
all those other beings, human and nonhuman, that make up one’s flesh:

If we can show that the flesh is an ultimate notion, that it is
not the union or compound of two substances, but thinkable
by itself, if there is a relation of the visible with itself that
traverses me and constitutes me as a seer, this circle which I
do not form, which forms me, this coiling over of the visible
upon the visible, can traverse, animate other bodies as well as
my own . . . [then] I can understand a fortiori that elsewhere
it also closes over upon itself and that there are other land-
scapes besides my own.³⁸

Just as the most minute change in one’s position can alter not simply the
“qualities” of any given object in the visual field but the entire tenor of
that field as flesh, we are caught up, captivated, and yet in cahoots with
others and the world in profoundly intricate ways.

Yet, that is not how most think about or experience health. There
is an argument to be made that the reverie of health, as sustained by the
dominance of *homo faber*, has become a paradigm of the times, metasta-
sizing, as it were, off of an individualism at the foundation of the larger
neoliberal geopolitical economy of the twentieth century.³⁹ Let us not forget
that much of biomedicine has historically operated with a “research takes
all” approach. That is to say, the bodies, minds, and well-being of those
under the auspices of medical care have too often come second or been
entirely disregarded for the ends of knowledge-building. This is especially
so with respect to bodies considered socially or politically disposable. The
Tuskegee and Guatemala Syphilis Experiments.⁴⁰ Forced institutional-
ization and sterilization.⁴¹ Henrietta Lacks, the Havasupai people, and
biological theft.⁴² Jim Crow medical care.⁴³ On the other side of this
Mobius strip of the value of health is the pervasive individual desire for
health and the demands we place—as citizens and consumers, patients
and practitioners, and workers and employers—to assure and insure it.

In order to understand a range of pressing ethical, social, political,
and philosophical implications of GSTs in general and the problem
of secondary variants in particular, I have suggested that one must, at
minimum, ask (a) the phenomenological question of *what it is like* for
parents and children and providers in this situation, (b) the evolutionary
biological question of *what it means* for an organism to have discovered

1 the genetic basis of its existence, and (c) the sociopolitical and normative
 2 question of *whether these practices contribute to justice* given the larger health
 3 concerns of everyone and especially historically oppressed groups. I have
 4 further suggested that Merleau-Ponty's concept of the flesh and his claims
 5 concerning the fundamental tension between macro and micro views
 6 (a) help us appreciate the complexity of this problematic and formulate
 7 responses to it and (b) that by linking his work to a further elaboration
 8 of the concepts of *homo faber* and *homo curare*, we get some traction in
 9 analyzing how this problematic relates to much larger existential issues.

10 To combat health as a reverie, to combat health as solely figured
 11 by *homo faber*, we (and who precisely constitutes this "we" must always
 12 be called into question) would need to prioritize care and community.⁴⁴
 13 We would need to articulate and realize the values of a future for health
 14 driven more equally by *homo curare*—a future that is truly egalitarian, by
 15 and for all. We would need, in other words, to replace health as individual
 16 reverie with health as social justice reality.

Chapter 10

21 1. Rosemarie Garland-Thomson, "Human Biodiversity Conservation: A
 22 Consensual Ethical Principle," *The American Journal of Bioethics* 15, no. 6 (2015): 14..

23 2. Maurice Merleau-Ponty, *The Visible and the Invisible*, trans. Claude Lefort
 24 (Evanston, IL: Northwestern University Press, 1968), 116; *Le Visible et L'invis-*
 25 *ible: Suivi De Notes De Travail*, Collection Tel 36 (Paris: Gallimard, 1979), 153.

26 3. My thanks to the participants of the 2018 International Merleau-Ponty
 27 Circle as well as Susan Bredlau and Talia Welsh for constructive feedback on
 28 earlier versions of this chapter. In the introductory paragraph to the chapter and
 29 in a few other spots, I have reused or modified a small amount of materials from
 30 Joel Michael Reynolds, "The Healtholocene," *Syndicate*, published November 12,
 31 2018. <https://syndicate.network/symposia/philosophy/kierkegaard-after-the-genome>. Reynolds's piece was an essay response to Ada S. Jaarsma, *Kierkegaard after the Genome: Science, Existence, and Belief in This World* (Cham, Switzerland: Palgrave Macmillan, 2017).

34 4. Jason W. Moore, ed. *Anthropocene or Capitalocene? Nature, History, and*
 35 *the Crisis of Capitalism* (Oakland, CA: PM Press/Kairos, 2016); Axelle Karera,
 36 "Blackness and the Pitfalls of Anthropocene Ethics," *Critical Philosophy of Race*
 37 7, no. 1 (2019).

38 5. Colin Koopman, *How We Became Our Data: A Genealogy of the Infor-*
 39 *mational Person* (Chicago: University of Chicago Press, 2019).

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6. Rosemarie Garland-Thomson, "Misfits: A Feminist Materialist Disability Concept," *Hypatia* 26, no. 3 (2011). 1
2
7. Maurice Merleau-Ponty, *The Visible and the Invisible*, 116; *Le Visible et L'invisible*, 153. 3
4
8. To be fair, the narrative medicine approach/movement is one area of medical education trying to counter this trend. See Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (New York: Oxford University Press, 2006). 5
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9. Aristotle, *Nicomachean Ethics*, trans. Terence Irwin, 2nd ed. (Indianapolis, IN: Hackett Pub. Co., 1999), 1.6. 8
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10. Charon, *Narrative Medicine: Honoring the Stories of Illness*; Mila Petrova, Jeremy Dale, and Bill Fulford, "Values-Based Practice in Primary Care: Easing the Tensions between Individual Values, Ethical Principles and Best Evidence," *British Journal of General Practice* (2006): 7. 10
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12
11. Maurice Merleau-Ponty, *Nature: Course Notes from the Collège De France*, trans. Robert Vallier (Evanston, IL: Northwestern University Press, 2003), 211. *La Nature. Notes. Cours Du Collège De France. Suivi De: Résumés De Cours Correspondants* (Paris: Le Seuil, 1968), 272. 13
14
15
16
12. A rich and fascinating literature has taken up the concept of homo faber in various ways across the last few decades. Due to considerations of space and the specific aims at hand, I do not engage that literature here, but I plan to in a future project. 17
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13. David T. Miller et al., "Consensus Statement: Chromosomal Microarray Is a First-Tier Clinical Diagnostic Test for Individuals with Developmental Disabilities or Congenital Anomalies," *American Journal of Human Genetics* 86, no. 5 (2010): 749–764. <https://doi.org/10/ckmnsx> 20
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14. Anita Thapar and Miriam Cooper, "Copy Number Variation: What Is It and What Has It Told Us About Child Psychiatric Disorders?," *Journal of the American Academy of Child and Adolescent Psychiatry* 52, no. 8 (August 2013): 772–774. <https://doi.org/10/f2xj89> 24
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15. Allison Werner-Lin et al., "They Can't Find Anything Wrong with Him, Yet': Mothers' Experiences of Parenting an Infant with a Prenatally Diagnosed Copy Number Variant (CNV)," *American Journal of Medical Genetics* 173, no. 2 (2016): 446. <https://doi.org/10/f9ptcp> 28
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16. Werner-Lin et al., 447. 32
17. Merleau-Ponty, *Nature: Course Notes from the Collège De France*, 211. *La Nature. Notes. Cours Du Collège De France. Suivi De: Résumés De Cours Correspondants*, 272. Due to space constraints, I am bracketing the question of how genetic counselors and other medical providers tasked with the delivery of such information interpret this scene. 33
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18. I explore many of the same studies analyzed here with respect to larger questions of epistemic injustice and the specific issue of ableism in Joel Michael Reynolds, "How Biomedical Technologies Harm Patients as Knowers," 37
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1 *Southern Journal of Philosophy* 58, no. 1 (2020): 161–185. I also reuse some small
 2 portions of the language from that article here, and my thanks to the editor for
 3 permission to do so. I am grateful to Allison Werner-Lin for first bringing my
 4 attention to qualitative work on these issues.

5 19. *Nature: Course Notes from the Collège De France*, 211. *La Nature. Notes.*
 6 *Cours Du Collège De France. Suivi De: Résumés De Cours Correspondants*, 272.

7 20. Maurice Merleau-Ponty, *The Visible and the Invisible*, 146; my emphasis.

8 21. Maurice Merleau-Ponty, *The Visible and the Invisible*, 139–140.

9 22. “What is Huntington’s Disease?” Huntington’s Disease Society of
 10 America. <http://hdsa.org/what-is-hd>

11 23. *Nature: Course Notes from the Collège De France*, 263. *La Nature. Notes.*
 12 *Cours Du Collège De France. Suivi De: Résumés De Cours Correspondants*, 330.

13 24. “Complementarity, n.” in OED, “Oxford English Dictionary,” in *Oxford*
 14 *English Dictionary* (Oxford, England: Oxford University Press, 2002).

15 25. David Morris, *Merleau-Ponty’s Developmental Ontology* (Evanston, IL:
 16 Northwestern University Press, 2018), 181.

17 26. Maurice Merleau-Ponty, *Nature: Course Notes from the Collège De France*,
 18 213, 217. Merleau-Ponty, *La Nature. Notes. Cours Du Collège De France. Suivi De:*
 19 *Résumés De Cours Correspondants*, 275, 279.

20 27. I am grateful to Erik Parens for the insight and insistence that binaries
 21 emerge from the failure to think their respective purchases on experience. The
 22 framework I present here of homo faber as a contrast with homo curare, creator
 23 versus carer—each as dimensions or modes of a greater whole—is directly inspired
 24 by Parens’s work. See Erik Parens, *Shaping Our Selves: On Technology, Flourishing,*
 25 *and a Habit of Thinking* (Oxford & New York: Oxford University Press, 2015).

26 28. I am thinking here especially of when Merleau-Ponty writes, expounding
 27 upon Edgar Dacqué, “the living being, reduction of fluctuation, sum of insta-
 28 bilities . . . the organism shows itself as a trap of fluctuation [*L’organisme monte*
 29 *lui-même un piège à fluctuation*].” Merleau-Ponty, *Nature: Course Notes from the*
 30 *Collège De France*, 263. *La Nature. Notes. Cours Du Collège De France. Suivi De:*
 31 *Résumés De Cours Correspondants*, 331.

32 29. J.A. Anderson et al., “Parents Perspectives on Whole Genome Sequencing
 33 for Their Children: Qualified Enthusiasm?” *Journal of Medical Ethics*, no. 43 (2016).
 34 There is a large and ever-growing body of research surrounding this context. I
 35 have consciously avoided wading through that research in this chapter in order
 36 to instead focus on what I take to be its central existential concerns.

37 30. Note that this is not just a question of what to do *as a parent*. Providers
 38 responsible for delivering and/or counseling about genomic findings report moral
 39 distress when parents decline it. Bernhardt et al., “Distress and Burnout among
 40 Genetic Service Providers,” *Genetics in Medicine* 11, no. 7 (July 2009): 527–535.
 There is also the question of the lived experience of the technicians and numerous,
 different labs who help decide the diagnostic line between variants of signifi-
 cance and unknown significance. We live in a political context where parental

obligations include compiling and acting upon as much medical information as possible. Indeed, we jail those who fail in particularly egregious ways. Despite uncertainty over the meaning of such information and its existential impact, the perception of increased control over a child's future seems, for many, to warrant overriding other concerns. While, as I've noted, genetic information is just one factor determining phenotypic expression and, furthermore, well-being, it certainly doesn't seem to feel that way for many parents today. This situation raises harrowing ethical questions: what are the conditions under which parents are presented with this choice? Which are the determinate factors—the differences that make a difference? And, perhaps most troubling of all for loving parents, whose welfare is ultimately at stake? What form does—and should—care take here?

31. Erik Parens and Paul S. Appelbaum, "On What We Have Learned and Still Need to Learn about the Psychosocial Impacts of Genetic Testing," *Hastings Center Report* 49, no. S1 (2019).

32. Linda Alcoff, "Epistemologies of Ignorance: Three Types," in *Race and Epistemologies of Ignorance*, ed. Shannon Sullivan and Nancy Tuana (Albany, NY: SUNY Press, 2007); Gaile Pohlhaus, "Relational Knowing and Epistemic Injustice: Toward a Theory of Willful Hermeneutical Ignorance," *Hypatia* 27, no. 4 (2012); Kristie Dotson, "A Cautionary Tale. On Limiting Epistemic Oppression," *Frontiers: A Journal of Women Studies* 33, no. 1 (2012); Joel Michael Reynolds and David Peña-Guzmán, "The Harm of Ableism: Medical Error and Epistemic Injustice," *Kennedy Institute of Ethics Journal* 29, no. 3 (2019): 205–242.

33. My thanks to Andrea Pitts for this point.

34. Among the many studies detailing these phenomenon in relation to health, see Jonathan Metzl, *Dying of Whiteness: How the Politics of Racial Resentment Is Killing America's Heartland* (New York: Basic Books, 2019). In section one, I focused on the question: will genomic health information, operating fundamentally as it does at a macro level, help you *know* how to care for *your* child? The problem with this framing should now be apparent: the myopic focus on genomic information concerning one's child misses the equitable health forest for the individualized health trees. It further misunderstands the social nature of health. As more than one study has shown, with respect to overall health outcomes, your zip code matters more than your genetic code. See Garth N. Graham, "Why Your ZIP Code Matters More Than Your Genetic Code: Promoting Healthy Outcomes from Mother to Child," *Breastfeeding Medicine: The Official Journal of the Academy of Breastfeeding Medicine* 11 (2016): 396–397, <https://doi.org/10/gt9sfx>. See also Harvard Medical School's study, "CaTCH: Claims Analysis of Twins Correlations and Heritability," <http://apps.chiragjppgroup.org/catch>. To help care for your child, you will need knowledge that spans the macro and micro—you will need local, community-based knowledge.

35. Maurice Merleau-Ponty, *Phenomenology of Perception*, trans. Donald A. Landes (Oxford & New York: Routledge, 2011), 446; *Phénoménologie De La Perception* (Paris: Gallimard, 1945), 483–484.

1 36. See Gail Weiss, “The ‘Normal Abnormalities’ of Disability and Aging:
2 Merleau-Ponty and Beauvoir” in *Feminist Phenomenology Futures*, eds. Helen
3 Fielding and Dorothea Olkowski (Bloomington: Indiana University Press, 2017).
4 I am thankful to Gail Weiss for noting that this raises very complex questions
5 about enhancement.

6 37. Eva Feder Kittay, “The Ethics of Care, Dependence, and Disability,”
7 *Ratio Juris: An International Journal of Jurisprudence and Philosophy of Law* 24, no.
8 1 (2011): 49–58. <https://doi.org/10/ffnrp2>

9 38. Maurice Merleau-Ponty, *The Visible and the Invisible*, 140–141; *Le*
10 *Visible et L'invisible*, 183.

11 39. Martha Fineman, *The Autonomy Myth: A Theory of Dependency* (New
12 York: New Press, 2004); David T. Mitchell and Sharon L. Snyder, *Biopolitics of*
13 *Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment*, ed. Sharon
14 L. Snyder (Ann Arbor: University of Michigan Press, 2015); Joshua Alan Ramey,
15 *Politics of Divination: Neoliberal Endgame and the Religion of Contingency* (Lon-
16 don: Rowman & Littlefield International, 2016); Jennifer Scuro, “The Ableist
17 Affections of a Neoliberal Politics,” *APA Newsletter on Philosophy and Medicine*
18 16, no. 1 (2016).

19 40. Britt Rusert, “‘A Study in Nature’: The Tuskegee Experiments and The
20 New South Plantation,” *Journal of Medical Humanities* 30, no. 3 (2009): 155–171.
21 <https://doi.org/10/b6qhkp>; Michael A. Rodriguez and Robert García, “First, Do
22 No Harm: The US Sexually Transmitted Disease Experiments in Guatemala,”
23 *American Journal of Public Health* 103, no. 12 (2013): 2122–2126. <https://doi.org/10/gf9gdr>

24 41. Nancy Ordovery, *American Eugenics: Race, Queer Anatomy, and the Science*
25 *of Nationalism* (Minneapolis: University of Minnesota Press, 2003).

26 42. Jessica L. Stump, “Henrietta Lacks and the HeLa Cell: Rights of Patients
27 and Responsibilities of Medical Researchers,” *The History Teacher* 48, no. 1 (2014):
28 127. Robyn L. Sterling, “Genetic Research among the Havasupai—a Cautionary
29 Tale,” *The Virtual Mentor* 13, no. 2 (2011): 113–117. <https://doi.org/10/gf9gdv>

30 43. Harriet A. Washington, *Medical Apartheid: The Dark History of Medical*
31 *Experimentation on Black Americans from Colonial Times to the Present* (New York:
32 Anchor Books, 2008).

33 44. Cf. Carolyn Neuhaus, “Does Solidarity Require ‘All of Us’ to Participate
34 in Genomics Research?,” *The Hastings Center Report* 50, no. S1 (2020): S62–S69.

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