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.
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> —Rosemarie Garland-Thomson[1]

> "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."
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> —Maurice Merleau-Ponty[2]

Introduction

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

Socially and politically, modern conceptions of health function as a stratagem or gambit. They assume a certain naiveté regarding the mortal necessity and curious transitions of aging, the social construction of normality, and the biological ambiguity of typicality—of the *typos*, the kind. This naiveté is profoundly productive. The fear of death and the changes it occasions are best tamed by never rising to the level of a fear: *I'm not afraid of dying; I just want to live life to the fullest*. The desire to be normal, to not be a *misfit*, is best tamed by being framed as a desire for flourishing: *I'm not against being different; I just want things to go more easily as I pursue my goals*.[6] The instinct to categorize things absolutely is best tamed by an impassioned fidelity to scientific method, the density of fact, and the gravity of the mean: *I'm not saying there aren't variations; I just want you to know how evolution has structured things.* Each of these strategies contribute in fundamental ways to the positive production of health, a production that garners and leverages untold amounts of capital and, far too often, functions to cover over a litany of historic and contemporary injustices baked into the fabric of each society it touches. The truism that "everyone wants to be healthy" is superseded in rank only by the assumption that there is such a thing as health—that health is an objective fact of the world by which we can produce objective knowledge 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 human as *carer*, that the idea of health will transform from a dangerous reverie into a more just reality.

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

Would You Like to Know When Your Child Will Die?

> *Your young child is exhibiting unusual physiological or behavioral symptoms. You have anguished over their meaning, maybe for months or even years—anguished over what may or may not be the case. At the suggestion of your medical provider, you agree to whole genome sequencing. 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. Not another's child or children in general, but* your *child. Genomic information will help one do this.*

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

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

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

Werner-Lin and colleagues detail the case of a mother who underwent 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 *fleshly* 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 already given us the *Einfühlung* [typically translated as "empathy"] of the body with perceived being (*l'être perçu*) and with other bodies. That is, the body as the power (*pouvoir*) of *Einfühlung* is already desire, libido, projection-introjection, identification."[19] The body, for Merleau-Ponty, is always already a scene of *em-pathy* understood in this expansive sense, a scene of what I understand in terms of and as defined by care. And the meaningfulness of bodily actions and bodily styles—from being a "really bad sleeper" as the first parent worries to having a "strangely mellow temperament" as the second parent worries—are interpreted in the light of enfleshed *Einfühlung*. In these cases that translates to a desire for normality, the fear of "becoming disabled," and the preemptive identification of their "true" child—the child they were supposed to have and/or the child who was supposed to develop—as "normal" and "healthy."

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

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

> *which is to say, all the many technological devices and programming algorithms that make possible in the first place the sequencing and analysis of genomes on the way to their diagnostic-prognostic interpretation.*

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

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

> [Genomic] information has standing as such only by virtue of ongoing and historical material and energetic dynamic flows that are part and parcel of what it takes to inherit genetic material and grow a body. These flows move through the medium of growing bodies in environments. We think the genetic information is there, right in and reducible to genetic material. But what we are really seeing when we (rightly) grasp genetic material as having an informative role is an effect of ongoing biochemical histories and dynamics washing through a body growing in this-here place.[25]

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

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

Existential Homeostasis and Existential Support

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

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

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

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

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

> SVs [secondary variants], conveying a sense of self-imposed obligation to take on the 'weight' of knowing [this information], however unpleasant.[29]

They found themselves in the thralls of duty, undergoing a deep normative pull, to take on the weight of this knowledge. Would you take on this weight?

> *After being told that there is secondary variant information, you, after much deliberation, decide to decline the information. Yet, if something happens down the road, how will you deal with knowing you might have mitigated it? If you accept it, won't that information affect how you treat your child? When and in what way will you tell them? How old is old enough to learn you might suffer an early death or will soon be living with some kind of illness or disease? Fifteen? Twenty-one? Forty? There are no easy answers and no easy way out of this dilemma once you're in it.*[30]

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

Justice and the Realization of Care

If, for homo faber, care is conducted as control over fate, conducted as a desire for existential homeostasis, then the scenes of care and the use of GSTs discussed above turn on the conversion of the fear of death as linked to abnormality into a knowledge that allows one to regulate or control that fear, the course of one's life, and the eventualities of one's ability transitions and ultimate death—and/or, by extension, that of one's loved ones. As Attic tragedy works to make clear, such knowledge 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 it seeks to uphold. For example, it must ignore aging,[36] adaptation, and the profound necessity of ability transitions and their many bearings and sendoffs; it must focus on the micro at the expense of the macro—taking the macro as having meaning only insofar as it affords the micro its desires; it must overlook and forget all the fluctuations, deprivations, and assaults on health that are not simply inevitable but which condition the possibility of life and any form of "health" within and along its course. And, ultimately, it must take on the form of a dogmatic idea that suppresses homo curare. Finally, to function as a reverie, health for homo faber must occlude the fact that we are beings of flesh.

In Defense of Reveries of Egalitarian Health

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

I have further suggested that insofar as modern ideas of health are based solely or unevenly on a conception of the human as homo faber, health functions not simply as any reverie but as a dangerous reverie that maintains unjust and inequitable systems of care. Health is not and never has been individual. It is a question of the reach of one's entire 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 landscapes 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, metastasizing, 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 institutionalization 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 in this situation, (b) the evolutionary biological question of *what it means* for an organism to have discovered the genetic basis of its existence, and (c) the sociopolitical and normative question of *whether these practices contribute to justice* given the larger health concerns of everyone and especially historically oppressed groups. I have further suggested that Merleau-Ponty's concept of the flesh and his claims concerning the fundamental tension between macro and micro views (a) help us appreciate the complexity of this problematic and formulate responses to it and (b) that by linking his work to a further elaboration of the concepts of homo faber and homo curare, we get some traction in analyzing how this problematic relates to much larger existential issues.

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

Notes

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

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

3. My thanks to the participants of the 2018 International Merleau-Ponty Circle as well as Susan Bredlau and Talia Welsh for constructive feedback on earlier versions of this chapter. In the introductory paragraph to the chapter and in a few other spots, I have reused or modified a small amount of materials from Joel Michael Reynolds, "The Healtholocene," *Syndicate*, published November 12, 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).

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

5. Colin Koopman, *How We Became Our Data: A Genealogy of the Informational Person* (Chicago: University of Chicago Press, 2019).

6. Rosemarie Garland-Thomson, "Misfits: A Feminist Materialist Disability Concept," *Hypatia* 26, no. 3 (2011).

7. Maurice Merleau-Ponty, *The Visible and the Invisible*, 116; *Le Visible et L'invisible*, 153.

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).

9. Aristotle, *Nicomachean Ethics*, trans. Terence Irwin, 2nd ed. (Indianapolis, IN: Hackett Pub. Co., 1999), 1.6.

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.

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.

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.

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

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

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

16. Werner-Lin et al., 447.

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.

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, "'What if There's Something Wrong With Her?': How Biomedical

Technologies Harm Patients as Knowers," *Southern Journal of Philosophy* 58, no. 1 (2020): 161–185. I also reuse some small portions of the language from that article here, and my thanks to the editor for permission to do so. I am grateful to Allison Werner-Lin for first bringing my attention to qualitative work on these issues.

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

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

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

22. "What is Huntington's Disease?" Huntington's Disease Society of America. http://hdsa.org/what-is-hd

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

24. "Complementarity, n." in OED, "Oxford English Dictionary," in *Oxford English Dictionary* (Oxford, England: Oxford University Press, 2002).

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

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

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

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

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

30. Note that this is not just a question of what to do *as a parent*. Providers responsible for delivering and/or counseling about genomic findings report moral distress when parents decline it. Bernhardt et al., "Distress and Burnout among 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 significance 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/gf9sfx. See also Harvard Medical School's study, "CaTCH: Claims Analysis of Twins Correlations and Heritability," http://apps.chiragjpgroup.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.

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

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

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

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

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

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

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

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

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