# Medical Humanities in Theory and Practice

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### INTRODUCTION

Over many generations medical knowledge has faced different stages of its development. At different historical periods medicine has acquired new features, which could either controvert the previous treatment practices or incorporate the existing accomplishments of the field in order to transform them into improved healing methods.

Nowadays, with the development of science and technology, most attention is paid to the efficiency and productivity of medicine, so the focus has shifted away from such important components as interpersonal, ethical and artistic aspects of medicine. The area of medical humanities is an important field, which combines knowledge from social, ethical and artistic studies, providing an understanding of these issues and teaching their right perception. The proper understanding of an increasingly broad cultural and social context is significant for the correct interpretation of various medical practices.

Some of the most important goals of medical science have always been for scientific advancement, offering essential knowledge for the diagnosis and treatment of various diseases; constant and significant contributions to the standards of medical education; and the promotion of ethical reflection in both scientific research and medical practices. Only the combination of these crucial components can result in the intended effect.

The interdisciplinary approach to medicine is an excellent way to facilitate controversial issues arising in different areas of medical studies, for instance, promoting new viewpoints on the relation between social sciences and medicine, and their impact on health, well-being and health care. Careful observation of such a relation suggests an enhanced or extended philosophy concerning the experience of medical practices.

Although the philosophy of medicine is becoming a more and more popular subject in the scientific community, still not enough attention is given to this field. Even in contemporary innovative programs dedicated to medical humanities, the philosophy of medicine is less allocated than medical ethics, the history of medicine, literature and medicine, and other areas in medical humanities. Nevertheless, sometimes applying philosophical principles to particular cases might be critical for improving medical practices. Both medical science and practice require examination at a variety of levels, so the philosophy of medicine can provide a view on the

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same problem from quite different angles and its more abstract analysis.

The present book discusses some philosophical aspects of medical science from the psychiatric and neuroscientific viewpoint; struggles to find the answers to important methodological questions, analysing the works of the famous philosophers in medicine and popular medical theories depicted in the works of well-known authors. It also focuses on bioethical problems and dilemmas which are of great importance nowadays; it describes the influence of various factors on the relationship between the physician and the patient and also analyses the reference to the human rights, their interpretation and implementation.

The article by William M. Joensen, "Normality, Ideology and Inquiry into Human Life in the Thought of Georges Canguilhem," is devoted to the concept of "life" as an irreducible principle in clinical science and human experience, and how a teleological view of human life endures despite the move to more positivist or evolutionist premises for investigation. In this vein the author examines the concepts of "norm" and "the normal" and their relationship to the "pathological" in humans and also touches briefly on Canguilhem's treatment of "information" and "error" as concepts operative in genetic medicine, proceeding to explore how human subjectivity introduces a moral dimension immanent to experiences of health and disease coincident with, but not fully determined by, our organic state. William M. Joensen addresses the role of culture and medicine, and the potential error of mistaking the genetic for the human—to an extent that corresponds with Canguilhem's theme of "scientific ideology" disseminated through scientific practice into society at large.

Michal Lytovka's article "Medical Knowledge: From the Synchronic Angle to Diachronic Transience" focuses on the concept of medical knowledge in the context of the geographical area and time period when it was or is used. The author outlines various points of view on disputable methods in medicine, criticising several practices which have been reconsidered in time and space. Transformation of the medical knowledge described in the article challenges the reader with the question of the future development of medicine and provokes thinking about possible derivatives of medical therapies.

Nataliya Shok's article "Pirogov vs. Galen: Philosophical Method in Medicine" is aimed at considering ideas in the fields of theory and practice of medicine. She highlights the important methodological role of the history of medicine in modern scientific research. Nataliya targets the investigation of the circumstances, emergence and development of the scientific method in medicine and identifies epistemological reserves for promising scientific discoveries, trying to find the answers to such

important methodological questions as: how substantial are the differences between the medicine of antiquity and that of the 19th century and if it is possible to assume the existence of a systematic appraisal of the approaches in medical theory and practice, with which it becomes possible to describe and analyze the prerequisites of discoveries at various historical stages.

In his paper "Practical Aspects of the Eleogenetic Approach to Therapy" Massimo Schino claims that the quality of the concrete and tangible encounter between the psychotherapist and the patient is essential in determining the destiny of the therapeutic act. He argues that both physical and mental factors regarding the so-called "setting" should be taken into careful consideration, since they are strictly interwoven. He also emphasizes the importance of paying close attention to the emotions and feelings unfolding while an encounter takes place. The claims in the article are supported with examples from home sessions with children, supervision sessions with educators of residential services, and flexible settings in collaboration with physicians.

In the article "Philosophy of Self—a View from Psychiatry and Neuroscience" Joanna Szczotka examines profound questions in philosophy: the notion of self, mind and consciousness. She discusses different traditions of thinking about self-consciousness referring to the works of famous philosophers and attempts to demonstrate the seeming inconsistency between the two approaches due to the fact that they take into account different levels of conceptualization of the self.

The article "Dignity of the Patient and Defensive Medicine" written by Daria Bieńkowska and Ryszard Kozłowski concentrates on the relationship between the physician and the patient, which is often destroyed by practising defensive medicine, and also human rights in such practice, which as the authors suggest sometimes seem to be forgotten or are freely interpreted. The authors want to demonstrate that despite many changes that have occurred in recent decades, the idea of human rights is essential to human dignity, the sacredness of life and personal inviolability. The authors believe that the nature of human rights requires its re-examination. The analysis of the subject carried out by experts in the fields of legal and philosophical sciences is based on the common foundation, which is the individual, and his life points to many critical issues that need to be thoroughly evaluated, as long as the subject is approached holistically.

Finally, Małgorzata Jarmołowicz in her article "The Human Search for Meaning in P. G. Hensler and J. Wakatsuki Houston's *Don't Cry, It's Only Thunder*. The Existential Analysis Perspective" explores the meaning-search-oriented attitude of the author-protagonist, Paul Hensler, whose

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story, depicted in the memoir *Don't Cry, It's Only Thunder*, is based on his own experiences of the Vietnam War. Applying the theory of existential analysis, or logotherapy, developed by Viktor Emil Frankl, the author focuses on the main tenets of his conceptual rationale through the prism of the protagonist's experiences in Vietnam, discovering the meaning of his life through creative, experiential and attitudinal values.

Andrzej Kapusta and Michal Lytovka, the editors

### NORMALITY, IDEOLOGY, AND INQUIRY INTO HUMAN LIFE IN THE THOUGHT OF GEORGES CANGUILHEM

### WILLIAM M. JOENSEN

In his play, "The Doctor's Dilemma," George Bernard Shaw lampoons London medical society in the early 1900s (Shaw 1913). The coterie of characters surrounding Sir Colenso Ridgeon-all "great men" in their own estimation—provides comic relief even as they disclose their own medical myopia in their search for objective cures: the surgeon Cutler Walpole wants to remove fictional organs as the etiology for all diseases rendered as "blood poisoning"; the general practitioner Sir Ralph Bloomfield Bonington is as bombastic as his name but generally clueless about medicine as he dilates about anti-toxins and the need to "stimulate the phagocytes" as the panacea for all ailments. And there is the skewed perception of the aforementioned Sir Colenso, whose clinical gaze fixes more upon the comely wife of the artist Samuel Taylor, thereby undermining all pretense of objective deliberation. All in all, the medical profession is depicted by Shaw as the domain of self-interested entrepreneurs, whose diagnostic acumen is fixed a priori by the premises and peccadilloes they impose upon their unfortunate patients. Whatever the actual medical judgment, the "doctor's dilemma" is always to be resolved toward the horn of self-interest.

Shaw's caricatures are withering, to be sure. But even if we presume beneficence, benevolence, AND competence, our depiction of present-day health care professionals and of the scientists who inform their practice is extended by the thought of another 20<sup>th</sup>-century intellectual: Georges Canguilhem. Canguilhem, a French historian and philosopher of science, and a physician who received his training between the two World Wars, is described as a "vital rationalist," but I contend that his philosophies of

<sup>1</sup> Canguilhem acknowledges that medical vitalism expresses an instinctive distrust of the "power of technique over life," while also conveying the "confidence the living being has in life, of the self-identity of life within the living human being conscious of living." He further recognizes how theories of vitalism expose

science and of medicine are neither strictly vitalist nor rationalist.<sup>2</sup> Canguilhem is helpful for examining our present situation particularly in genetic medicine, not only because he had one foot in medicine and one in philosophy, but because his research draws upon different philosophical traditions.<sup>3</sup>

In my paper, I take up: (1) the concept of "life" as an irreducible principle in clinical science and human experience, and how a teleological view of human life perdures despite the move to more positivist or evolutionist premises for investigation. In this vein, (a) I examine the concepts of "norm" and "the normal" and their relationship to the "pathological" in humans; (b) I also touch briefly on Canguilhem's treatment of "information" and "error" as concepts operative in genetic medicine.

(2) I proceed to explore how human subjectivity introduces a moral

themselves to criticisms of being "scientifically retrograde" when vitalism is not properly distinguished from the sort of "animism" evident in the work of Georg Ernst Stahl: "the theory according to which the life of the animal body depends on the existence and activity of a soul endowed with all the attributes of intelligence . . . acting on the body as one substance on another, from which it is ontologically distinct." "Vitalism contaminated with animism thus encounters the same criticisms, at once philosophical and political, as dualist spiritualism" (Canguilhem 2008: 62, 71).

- 2 Monica Greco comments on the "vitality of vitalism" and the "semantic polyvalence of vitalism," in one sense referring to metaphysical principles, teleology, and the opposition to mechanism—the so-called "animist view" that one can associate with Plato, Hans Driesch, and Bergson's élan vital. In contrast, "naturalistic vitalism" "posits natural laws that transgress the range of physical explanations." Greco is not enthused about Wuketits' systems theoretical approach that replaces any residue of vitalism with an "organism-centered view of life" that he identifies as "holism." Greco, pace Stengers, instead prefers to speak of "complexity" for "deciphering the vital supplement": "It is both possible to regard the living as a fundamentally natural object, equal in the sense to the objects of physics and chemistry, and impossible to extend physico-chemical models . . . to account for the living" (Greco 2007: 41-58).
- 3 Canguilhem issues a caveat for the life scientist who turns to philosophy who "thinks he brings a certain capital with him to philosophy, but in reality he brings to it only a land-income [rentes], which continually decreases in the market of scientific values—for the simple reason that research, in which he no longer participates, continues to move forward" according to its own "internal dynamism." There is no cheap consolation in philosophy, for "philosophy, being an autonomous enterprise of reflection, does not honor any prestige at all, not even that of the scientist, or—even more rightly—that of the ex-scientist" (Canguilhem 2008: 68-69).

dimension immanent to experiences of health and disease coincident with, but not fully determined by, our organic state. (3) My next and concluding sections address the role of culture and medicine, and the potential error of mistaking the genetic for the human—to an extent that corresponds with Canguilhem's theme of "scientific ideology" disseminated through scientific practice into society at large. His analysis heightens our concerns about the ethical ramifications of genetic interventions into human life. Life is Canguilhem's first principle. Life is implicated in the nucleotide sequence; it imposes its form and deformity into our clinics and our consciousness.

### Life, Normality, and Pathology

Even though there have been different connotations of the word "normal" over the past century, "normality" is Canguilhem's term for expressing the thematic continuity of life in individual organisms. Biological objects resist reductivist explanations on the basis of parts: "In biology objects appear which are characterized by increasingly distinct uniformity, individuality, and totality" (Canguilhem 1991 [hereafter, "NP"]: 217; cf. Canguilhem 1988 [hereafter, "IR"]: 127).

Life is constantly engaged in a dynamic, homeostatic polarity of propulsion and repulsion. Canguilhem recognizes, "Because the qualified living being lives in a world of qualified objects, he lives in a world of possible accidents. Nothing happens by chance, everything happens in the form of event." The inconstancy of the environment is simply part of an individual's becoming, its history (NP 197). "Science explains experience, but it does not for all that annul it" (NP: 198).

Canguilhem's doctrine of life differs from an evolutionist approach which maintains that the principal goal of life is genetic survival via reproductive transmission. His concepts of "norm" and the "normal" signify the natural necessities immanent to the development and sustenance of life: "Wherever there is *life* there are norms. Life is a polarized activity, a dynamic polarity, and that in itself is enough to

<sup>4</sup> Cf. Robert Spaemann, drawing inspiration from C. S. Lewis, who details the historical unfolding (dis-)regard for the totality of living entities: "In Rousseau, reason becomes a late epiphenomenon of a creature's originally irrational and undetermined nature. Another hundred years later, life becomes the epiphenomenon of molecular macro-structures. Now this process, the loss of teleology, certainly yields an enormous increase in knowledge; the 'reconstruction' of our origin allows us to see through in an ever-more-sophisticated way the construction laws of all that lives" (Spaemann 2010: 18).

establish norms. The normal is therefore a universal category of life" (Canguilhem 1994b [hereafter, "VR"]: 351). These norms are inherent to the living being, which is present in itself in a manner that transcends the sensible perception of extended objects. Canguilhem states,

Strictly speaking, there is no distance between organs within the organism, no externality of parts. . . The organism itself does not live in the spatial mode by which it is perceived. *The life of a living being is, for each of its elements, the immediacy of the co-presence of all* (emphasis added; NP: 253).<sup>5</sup>

The parts of the organism are functionally integrated to an extent that—despite Canguilhem's occasional speculation at other places—entails ontological unity.<sup>6</sup>

Consistent with Kant, Canguilhem prefers to speak of "finality" rather than teleology (VR: 309-11). Cognizance of individuality and finality is concomitant with awareness of ontological boundaries implied by life—awareness that may not suit the scientist's standard of clarity and objective rigor. The individual totality is a theoretical limit to division, and also limits efforts to dissolve the existing entity into a larger, moral whole. Individual integrity holds ontological priority over epistemic dispositions to place the parts before the whole, or to theoretically reduce the whole to a mere part. 8

The concept of finality also points to a different sense of limitation. The acknowledgement of life's complex of ends is met with the possibility that the comprehensive end will not be realized. There is a host of physical and psychic insults to bodily and cognitive integrity and functioning producing pain, deformation, and disease. For Canguilhem, the organizing principle of nature is not health, disease, or even death: it is life. He states, "Life rises to consciousness and science of itself only through maladaptation, failure, and pain" (NP: 209). He borrows from Foucault's description of the modern investigative move in medicine: "Bichat made

<sup>5</sup> Cf. Canguilhem VR: 318, Canguilhem 1983: 363.

<sup>6</sup> To predicate the "normality" of a living thing is to speak about it obliquely, not directly; cf. Canguilhem's comments in the course of disagreeing with Claude Bernard: "Normality is not a quality of the living thing itself but an aspect of the all-encompassing relation between life and death as it affects the individual life form at a given point in time" (IR: 137).

<sup>7</sup> Canguilhem VR: 309-11; Cf. Canguilhem 1983: 343-45, also 326-27, 354-60. Yet, for Canguilhem, the claim that organic life is still irreducible still stands (IR: 132; cf. VR: 68).

<sup>8</sup> See VR: 170-77; cf. Canguilhem 2008: 70.

'the medical gaze pivot on itself', in order to call death to account for life' (NP: 285). But where Foucault postulates a "technical and conceptual trinity" of "life, disease, and death" with death given primacy, Canguilhem's model gives conceptual priority to life (Foucault 1994: 144-46).

The present capability to genotype each person in his or her polymorphic distinctiveness was anticipated in a different manner two centuries ago, when anatomo-pathological perception offered to clinical examination "what, for it, had remained for so long the visible invisible—the forbidden, immanent secret: the knowledge of the individual" (ibid.: 170). Today genetic testing may provide an unprecedented level of material description, but cannot resolve the existential opacity of transcendental formalism (of either philosophical or scientific provenance) with the tendency to efface the individual. A formal approach is either uninterested in, or denies that we have access to the "natures" of the personal and pathological objects that clinical scientists encounter.

Where Foucault commends this version of a formalist, positivist medicine, he and Canguilhem part company. The differences between their doctrines are clearly seen in their contrasting understanding of the concept of "finitude," which (with Foucault), I associate with the concept of "limit." For Canguilhem, death and disease retain their classical character as metaphysical evils. Life is the *a priori* principle of existential good. The event of death discloses the form of life. Death marks a temporal origin in our order of knowing. Yet in the order of existence, it is the living organism whose principle of life is most knowable in itself, and thus assumes ontological priority.

Canguilhem criticizes the mistaken attribution of absolute ontological continuity between normal and pathological states of human nature—a mistake he imputes to Auguste Comte and others.<sup>10</sup> The use of a linear numerical scale in order to categorize biologic states effectively "annuls pathology" (NP: 42).

For all intents and purposes, Canguilhem's concept of the "abnormal" is commensurate with the "pathological" (NP: 182). In the typical experience of disease, a qualitative alteration occurs in a person prior to the subjective awareness that something is wrong in life. Clinical precedence propels theoretical pursuit; we seek causes and remedies for conditions we

<sup>9</sup> Cf. Foucault 1994: 197-99; Canguilhem 1994a: 84. As alluded before, Canguilhem stresses the ontological integrity and supra mathematical objectivity of nature in a manner that retains greater continuity with classical forebears (cf. VR: 72-76, 80-86, 317-18; Canguilhem 1983: 326-63).

<sup>10</sup> Cf. Canguilhem NP: 71-74; see also NP: 248-50 for an etymological and historical overview of the term "norm."

identify as problems in our personal world (NP: 88). Discernible functional diminishment evokes our desire to understand ourselves. "Pathos conditions logos; the abnormal evokes interest in the normal" (NP: 208-9). Similarly, "The abnormal, while logically second, is existentially first" (NP: 243; cf. VR: 383). The subjective judgment of patients is decisive for defining any felt imbalance in the "polarity" of their lives as diseased or healthy states. Physicians and scientists act as diagnostic informants, therapeutic adjutants, but the assessment of whether there has been a meaningful rupture among the comprehensive (biological, relational, and spiritual) aspects of life is ultimately left to the patient.

Concepts of "norm" and the "normal" represent a theoretical bridge between the corporeal aspect of human beings and their capacity as intelligent beings to contemplate their own natural state. Attention to how "normal" is employed alerts us to scientific and social influences affecting the evaluation of various physiological and genetic states as either positive or negative, good or evil. And it is correlated with the terms "information" and "error" in the genetic context, with the possible sequela of contributing to theoretical currents that not only aim to treat disease, but to genetically enhance those otherwise considered to be "normal."

#### **Error and Genetic Information**

In the scientized ontology surfacing in the early part of the twentieth century, Canguilhem suggests, "Heredity is the modern name of substance" (NP: 280). In the context of contemporary evolutionist, determinist theories, the judgment of a particular life as "error" is particularly cogent. In the beginning of the twentieth century, descriptions of hereditary biochemical diseases such as phenylketonuria and other conditions composing the genetic ordering of metabolism were labeled "errors." With its roots in information theory, Canguilhem observes how the concept of error first "rested on the ingenuity of a metaphor; today it is based on the solidity of an analogy" (NP: 276). Those who conceive "error" in this fashion also modify the concepts of "health" and "disease." Genetic disease may alter

<sup>11</sup> The "normal" is not univocally synonymous with the "natural," but it is one means of expressing the form and function of living beings. The normal, which is understood in a "Canguilhemian" and not in a "Comtean" way, refutes the tendency toward a reductivist, eliminativist approach to human life.

<sup>12 &</sup>quot;Genetic mutations that block chemical syntheses by altering their enzyme catalysts are no longer interpreted as deviations in Maupertuis's sense but as errors in reading the genetic 'message', errors in the reproduction or copying of a test" (Canguilhem IR: 140).

the perception of the whole person: "Health is genetic and enzymatic correction. To be sick is to have been made false, to be false . . . in the sense of a 'false fold' or false rhyme" (ibid.). The concept of error can contribute to the conflation of epistemic and ontological orders, with resulting confusion in the areas of clinical and political practice.

Geneticists must be able to make qualitative distinctions between anomalies that are individual morphological and functional variations consistent with comprehensive health and those deviations from "typical" appearances and operations that result in diminished states of life (NP: 277). The detection of wide-ranging deviation from statistically-derived norms of biomedical phenomena does not automatically indicate disease (NP: 136). In fact, along the diverse axes of biochemical, neurological, and physical functions that can be measured, it is the composite of respective deviations from the mean that is descriptive, if not explanatory, of human individuality. 14 Composite deviation without gross phenotypic pathology reflects the irreducibility of life (NP: 154). We are all "extreme" in at least several traits or susceptibilities. But to equate the error that is polymorphic variation with the error that is abnormality or disease is to make a categorical mistake. Camille Limoges states, "It is genetic 'errors' that made us as a biological species: we humans are integrated aggregates of such 'errors'" (Limoges 1994b: 124).

Canguilhem emphasizes genetic idiosyncrasy as a valued feature of the "normal." Even error does not in itself constitute disease; it stands closer to the concept of "chance." Foucault observes, "Error for Canguilhem is the permanent chance around which the history of life and that of men develops" (Foucault 1991: 22-23). Genetic abnormalities (pathologies) include biochemical deletions, disruptions, and repetition of nucleotide

<sup>13</sup> Canguilhem himself substitutes molecular information for numerical quantity as a new normal concept with both theoretical and material referents. As a result, the multivocality of "information" correlates to the "polysemy" of "error": "To know is to be informed, to learn to decipher or decode. There is then no difference between the error of life and the error of thought, between the errors of informing and informed information" (NP: 277).

<sup>14</sup> Snyder, Du, and Gerstein note that there are approximately three to four million single nucleotide polymorphisms (SNPs) in a given individual relative to the international sequencing project collective DNA reference genome; there are ~0.3-0.6 million small insertions and deletions (Indels) present in a given individual. Further, when it comes to large structural variations (SVs), which consist of deletions, insertions, and inversions greater than 1000 base pairs (bp), and include transposons such as L1s which comprise one-third of the >1 Mb size SVs; "there are at least 1000 SVs >2 kb in size present in a given individual relative to the reference genome" (Snyder et al. 2010: 423-24).

sequences. They are connected, but not coextensive, with the progressive and prospective phenotypic manifestation of genotypic "errors." If life bears meaning in the form of information, "we must accept the possibility of a loss of that meaning, of distortion, of misconstruction. Life overcomes error through further trials (and by error I [Canguilhem] mean simply a dead end)" (IR: 318).

I have recounted how Canguilhem distinguishes between anomaly and disease. All persons are originally anomalous. Some are also originally abnormal. And many of us come to know ourselves as actually possessing pathological conditions at some point in our personal experience, i.e., that we are diseased. The scientist possessing epistemic subtlety and clinical reserve will respect the phenotypic silence of many genetic anomalies. The forces of chance may actually work in a person's favor. The relative "silence" of genetic anomalies or errors is compatible with Canguilhem's definition of health. Further, there is a paradox rooted in the observation that self-conscious preoccupation with the state of one's health is usually an indication that something is amiss (NP: 91, 118). The excessive concern for one's own health is often a disclosive premonition that pathology is present, whether physical or mental in nature (NP: 286-87).

# The Human Significance of Normality, Health, and Disease in Light of Genetic Alteration

The concepts of "health" and "disease" are closely related to the estimation of value. <sup>15</sup> Canguilhem defines "disease" as "behaviour of negative value for a concrete living being in a relation of polarized activity with his environment" (NP: 223). He elaborates:

Diseases are crises in the growth toward the adult form and structure of the organs and in the maturation of functions of internal self-conservation and adaptation to external demands. They are also crises in the effort undertaken to live up to a model of selected or imposed activities and, in the best cases, to defend the values of or reasons for living. Diseases are a ransom eventually to be paid by men made to live without having asked for it, who must learn that they necessarily tend, from their very first day,

<sup>15</sup> The positivist's error in translating the quantitative grade of the normal and pathological into an ontological scale may be repeated at the axiological level. In this attitude, to speak of the "normal" is to articulate an ideal by which all instances can be measured and evaluated (NP: 125-26). When this occurs, "Those who make the normal a fact have valorized their need for limited meaning," and have overlooked the "polysemous" character of the normal (NP: 236).

toward an unforeseeable and inescapable end (Canguilhem 2012: 40-41).

Disease is a present state of the person eliciting a definite cognitive—and likely also affective—response. There is an objective dimension that includes any clinical data, and is rooted physically in time and place. There is a stronger subjective element implied in his definition of disease than there is for pathology (NP: 201).

At a foundational level, disease is a loss of homeostatic flexibility in the face of fluctuating environmental conditions. Pathology is a qualitative change in the living organism; this change is termed "disease" when the fact of a change and its attendant limitations are imposed upon a subject's consciousness. The awareness of, and acquiescence to, these personal limits are themselves phenomena representative of disease. Disease is "intolerance" of change (NP: 199).<sup>16</sup>

"Judgments of disease all form a judgment of virtual value" (NP: 121). And this judgment is ultimately rendered by the prospective patient rather than by the physician, although usually the two cooperate in reaching a judgment. Judgments about the presence or absence of disease may be based in science, but they are also moral judgments. The relations of the normal and the pathological, and of health and disease, are asymmetric and contingent upon individual subjects. Canguilhem's emphasis on the subjective aspect of disease seems to reflect his reliance upon Kantian categories where he affirms the value-seeking, value-sustaining, and value-creating dimension of human conduct in the context of health and disease. Contra Descartes, health is an equilibrium that enables the pursuit of other values; health does not represent the sum or ultimate goal of these values. Using an athletic metaphor, Canguilhem says that the healthy individual seeks to "tackle" existence, although he criticizes the "seductive image" of the athlete employed by positivist physiologists and clinicians (NP: 201).17

The affirmation of the good of health correlates to the identification of disease as a form of evil for the existing being. An objective disease ontology

<sup>16</sup> Cf. Canguilhem 1994b: 354-55.

<sup>17</sup> Elsewhere, Canguilhem describes "health" as the "feeling of a capacity to surpass initial capacities, a capacity to make the body do what initially seemed beyond its means. We rediscover the athlete. A line from Antonin Artaud, which concerns, first of all, human existence under the guise of life, rather than life proper, can serve to help us define health: 'We can accept life only on condition of greatness, only if we feel ourselves at the origin of the phenomena, at least of a certain number of them. Without the power of expansion, without a certain domination over things, life is indefensible'" (Canguilhem 2012: 49).

is connected with a robust anthropology (cf. VR: 127). If existential values are affirmed as objective goods, then the therapeutic response to the "evil" of disease is a form of "valorization." If on the other hand, disease is characterized either as "deficiency" or "excess," then therapy is construed as "compensation" (NP: 275).

The experience of disease, despite its negative connotation, is an occasion to apprehend existential truths, and to become more completely human. Disease, according to Canguilhem, is a form of self-consciousness. Contemplating the prospect of disease makes man conscious of himself, and affords him the chance to reflect on what it means to be human, to live, and to die. Disease evokes consideration of our human nature. It allows us to refine our perception of what human life truly is. The possibilities introduced by disease are identified in a strikingly appreciative tone. "Diseases," says Canguilhem, "are new ways of life" (NP: 100). And more directly, he claims:

Disease is a positive, innovative experience in the living being and not just a fact of decrease or increase. The content of the pathological state cannot be deduced, save for a difference in format, from the content of heath; it is a new dimension of life. (NP: 196)<sup>18</sup>

Canguilhem identifies a transcendent aspect of life manifested in disease. Awareness of human disease evokes that which is most paradigmatically human: the confrontation at physical, psychic, and spiritual levels with adversity, with the privative aspect of life. This experience beckons for willed response, for relationship, for transcendence. Canguilhem develops Aristotle's insight (in a way that Kant might also recognize): "Physiology is like all science, which, as Aristotle says, proceeds from wonder. But the truly vital wonder is the anguish caused by disease" (NP: 101).

The experience of disease is cause for wonder, not simply fear or reproach. Disease elicits the capacity of humans to go beyond existing contingencies of life and provisional purposes. The deformations of bodily functions and intellectual aims in life wrought by illness elicit human responses of human compassion, deliberation, judgment, and willed intervention or abstention. The "normal" sick person is moved to seek

<sup>18</sup> On a sheer physiological level, "Certain diseases can, after recovery, confer on the organism a capacity to resist others. To grow old, to last, if not unscathed, then at least toughened, can thus also be the benefit of having been sick." Nonetheless, "Diseases are instruments of life by which the living (when it is man we're talking about) see themselves forced to avow their mortality" (Canguilhem 2012: 41).

assistance in healing, to enlist nature's own restorative potential, and to reconfigure existential chaos into a new, personal life-world. There is the possibility of a new subjective whole, implicitly given, if not definitively apprehended, in the irreducibility of life, especially human life.

Humans are not solely determined by their bodies or by their previous judgments. They can rediscover or establish an order of life that respects, but is not subordinated by, the materialistic aspect of natural forces. They can also go beyond former contingencies. Genetic scientists and clinicians may point the way to this restored order of life by identifying certain causes, providing information, and delivering therapeutic means.

The values at stake in genetic interventions are already manifested where the presence of a human life is recognized. These values delimit and guide subjective cooperation by patients and clinicians with the human nature whose origins already inscribe the ends of human striving. There are moral features intrinsic to the human efforts to investigate, treat, and prevent the possibility of genetic "errors" diseases. And there are moral goods immanent in the aspirations to transcend disease, present in the very possibility of locating meaning and value apart from any actual correction or cure.

In the modern dispensation, cognizance of death and personal finitude do not necessarily engender their acceptance. Humanity turns ever more urgently to the technical armamentarium that promises to carry individuals beyond life's natural limits. Medicine offers a semblance of hope to some because it represents a potential escape from finitude. But medicine can also keep us from recognizing and respecting our true human finality—in moral and metaphysical, and not simply biological, senses. The motivation for genetic enhancements (apart from the diagnosis of prospective or actual disease) has deeper roots than the technical developments of recent generations have made possible.

Humans themselves present the greatest challenge to the theoretically normal life, concomitant with the propensity to confront natural limits by trying to transcend them. There is a transcendent impulse to human nature—regardless of whether one is an athlete. Humanity's "prodigal" natural capacities are being increasingly supplemented by technological means. Technological modification knows no "natural limit"; the excesses of infinite ideals and unlimited desires could actually be pathological for human life taken in its most comprehensive sense.

There is a moral temptation posed by the opportunity for genetic selfalteration or the alteration of one's progeny. Humans can actually

<sup>19</sup> Canguilhem remarks, "Man feels supported by a superabundance of means

introduce moral and spiritual limitations that exceed those already communicated by the fact of biological existence. The practice of medicine and other clinical sciences can be enlisted in this co-opting of vital values. Adults are normally free of the illusion that desire and reality can be immediately harmonized, but are liable to reverting to what Canguilhem calls the "puerility of myth". He contends, "The modern adult has limits which must be overcome, but they cannot be overcome by returning to a mode of thought which ignores precisely that there are limits to desire in reality and obstacles to value in existence" (VR: 362).

The mythic imagination aspires to transcend certain existential limits, but can even become "malignant" [my term] to the point of denying that there are given limits upon desire. Practical aspirations are shorn of the sense of limits in the form of natural necessities and ordered ends. Humans who accept the technological illusion of manufactured satisfaction may indeed aspire to become the "complete man of which children dream" (VR: 363), but their dream is a much more diminished one, and their hope of fully flourishing is truncated.

The clinical sciences contribute theories of human functioning and establish norms that may be combined in the ideal of the theoretically "normal" human. Canguilhem does not comment directly on the genetic modification of organisms apart from practices that terminate human life. I speculate that he would find genetic interventions to be misguided and presumptuous—even from the perspective of evolutionist biology—when they are aimed at maximizing the incidence of selected traits absent from the judgment of present or incipient pathology. "Artificial," rather than natural selection, even for purposes of enhancement, would reduce overall genetic variety and species vigor.

The human desire to transcend preexisting norms of life may animate efforts to minimize the place of chance, the potential for error. However, the "remedy" for "error" may be worse than the existential event itself. Efforts to counteract and prevent genetic error can lead to a personal and social climate where the rational ideal of perfection, of the inerrant, of the "more" human, produces a new intolerance toward those who are metaphysically "mistaken." Interventions that proceed from theoretical origins independent of existential conditions make therapeutic intentions more ambiguous, even suspect. The "normal" becomes even more formalized than it already is. The normal standard may come to reflect a socially stimulated, technologically generated need, rather than a perception contingent on the objective state of one's organism.

Today, many scientists perceive their task as one of "deconstructing" and "constructing" the forms found in human society and the world—theoretically and literally. And in their analysis and synthesis, there is a tendency to confuse the terms of description, some of which are metaphorical, with the terms of definition. We are nigh on the verge of committing a new theoretical error in response to the "error" of chance genetic inheritance (within normal ranges) when we think that by making our capacities the object of medical intervention, we will know ourselves better and thereby satisfy our intelligible desires. Or we will err practically in believing we are more likely to fulfill our bodily-borne capacities simply by changing them. We can divert our attention from the order of ends to which our own human nature directs us, and visit error in Canguilhem's sense of "dead end." We are liable to conclude our lives no more fully-formed or informed than we were at the beginning of our conscious quest.

# Genetic Essentialism and the Pursuit of a Truly Human Life

In some pronounced instances, definable patterns of thought have emerged as scientific and social ideologies. They compose a certain "barometric pressure" exerting influences upon the atmosphere of genomic science and our collective attitudes toward our new-found technological powers. Canguilhem characterizes *scientific* ideologies as "explanatory systems that stray beyond their own borrowed norms of scientificity" (Canguilhem IR: 39). A scientific ideology is not to be confused with false science. Rather, "it derives its impetus from an unconscious need for direct access to the totality of being, but it is a belief that *squints* at an already instituted science whose prestige it recognizes and whose style it seeks to imitate" (IR: 38).

I suggest, in the spirit of Shaw's play, "The Doctor's Dilemma," that there is a distinct genus of "medical ideology," where discourse parallels the development of science, but under the pressure of pragmatic needs,

<sup>20</sup> Among the enthusiastic and expansive claims at the International Summit on Gene Editing held on 1-3 December 2015 in Washington, DC, John Harris of the University of Manchester [England] observed that human gene editing provides a means of evolving "by a process much more rational and much quicker than Darwinian evolution. . . What is clear is that we will at some point have to escape both beyond our fragile planet and beyond our fragile nature. One way to enhance our capacity to do both these things is by improving on human nature" (Olson 2015; 3-4).

makes claims that overextend its proper competence, and is thus presumptuous in believing that ultimate solutions may be proposed whether research is still in process or not. This sort of ideology is eminently operative for the human subjects who fall under the clinical gaze, as well as those who survey society and apply a scientifically utopian metric to social polity and programs.

A contemporary species of medical ideology is "genetic essentialism," which can be defined more precisely as a theoretical genus which posits that the genes themselves have causal agency in both material and ontological senses: (1) genes are responsible for assimilating material and organizing the developing individual; (2) genes direct the organism's enduring processes of metabolism, reproduction, sensation, and for humans, cognition; and finally, (3) genes are the "form" conferring unity, species-identity, and existence upon the organism. With metaphorical tongue-in-cheek, one might say that genes represent the ingredients, the recipe, and the *sous-chef* for life. Properties of vitality and cognition are ultimately attributed to the complex of discrete genes. Genes, if not independently sufficient for life, are the predominant cause for life. More than for any other element or principle, it is said that genes *are* life.

Genetic essentialism thus represents the "straying" of genome science to philosophical anthropology, ethics, market-place economics, and metaphysics. Among the collocation of diverse theoretical interests, the gene is at once "super-" or "hyper-real," with separate, near-substantial status; it is simultaneously ideal, a notional process dissociated from its proper material foundation (cf. Canguilhem IR: 117). The genome and the genes which compose it are *bona fide* scientific objects, but they are not naturally so.

Strikingly, more recent understandings of DNA sequence information and transcription mechanisms actually decentralize the gene—spatially and semantically. Many biologists, Gayon says, "no longer believe in the existence of a non-ambiguous entity that can be called a 'gene'" (Gayon 2000: 294-95). The DNA sequence associated with a particular functional expression is not strictly demarcated, nor is it necessarily stable within a particular roughly bounded sequence. There is greater fluidity in gene concepts, and a greater engagement of formerly distinct disciplines in biology, fostered by the empirical discoveries in genome science.

The functional biochemical complex termed "gene" is therefore a necessary but insufficient precondition for the development and ongoing existence of the organism. The gene can thereby be deployed to further

<sup>21</sup> See Keller 1994: 91; Keller 2000: 277; cf. Canguilhem VR: 315-16.

any combination of scientific, medical, and ideological purposes. Though clinicians, ethicists, and policy-makers seek objective criteria upon which to base their judgments about the sorts of genetic variations and mutations that are truly deleterious for persons, there is an inherent subjective element in judgments of health and disease.<sup>22</sup> There is no reason to surmise that the degree of subjectivity will abate with a burgeoning sequence and linkage data. Interpretive dispositions are even less credible when the personal stakes scientists have in ensuring that research enterprises prosper are revealed.<sup>23</sup>

Personal experience, even the patient himself, is effaced in the shifting of criteria for health and disease to whatever is contained in the DNA sequence (Keller 1994: 97). The *normal* person is increasingly identified as the one with the *optimum* genome, with the ideal constellation of traits. There is a kind of systemic political pathology analogous to genetic essentialism. Ideological schemes are not restricted to scientific technical endeavors, but are linked to a broader social philosophy. Comte's positivist understanding of organic pathology has its counterpart in the regulative social program he proposes (Canguilhem NP: 251-52).

Even if the combination of medical genetic interventions, elevated standards of normalcy, and unfettered personal autonomy does not immediately result in greater social inequity, there is another kind of estrangement that geneticist ideology may introduce. We can be led to a distorted view of our own humanity. The fecund accomplishments of the new human genetics do not teach us what it means to be human. They do not automatically elucidate or contribute to human order and flourishing, but may insinuate social disorder (Keller 1992: 298).

While it is certain that some will arrogate to themselves the responsibility for elaborating the humanly "normal," the potential peril of geneticization involves transposing judgments of "good" and "bad" genes to judgments

<sup>22</sup> Gina Kolata reports the instance of Angie Watts of North Carolina, USA, who tested positive for a gene mutation sometimes associated with breast cancer, but who received opposing opinions about whether in fact it was deleterious. "A group of doctors met but could not reach a consensus, so, Ms. Watts said, 'they left it up to me to decide' [whether to have a double mastectomy]. 'Our ability to sequence genes has gotten ahead of our ability to know what it means', said Eric P. Winer, the director of the breast oncology program at Harvard's Dana-Farber Center Institute. . . 'The stakes are very high', said Dr. Evans, the geneticist who counseled Ms. Watts. 'You have inherently nuanced and confusing tests and widespread ordering and interpretation by doctors who aren't really equipped to do so', he said. 'The situation is ripe for over interpretation and misinterpretation' (Kolata 2016: 6).

<sup>23</sup> See, e.g., Hubbard and Wald 1993; Goodyear 2016.

about which lives are valuable or not. We can aim at a standard of human invincibility to disease, and risk becoming contemptuous of human vulnerability, and actual disability.

Concomitantly, the correlation between individual free choice and genetic (ab)normality is concomitant on a key factor: ignorance. "The very possibility of choice depends on a domain of agency that can remain free only to the extent that it remains unexamined" (Keller 1992: 299). Evelyn Fox Keller observes that in this genetically essentialist context, freedom is inversely proportional to what we know about ourselves—at least in a genetic sense. If the genetic catalogue of the human and the molecular derivation of normality are what matters most in defining our humanity, then we are in a curious position. Our inclination for bodily health, our desire to preserve individual autonomy, and our desire to understand the world and ourselves are difficult to reconcile. Ironically (and contrary to the Socratic injunction), we may be better off not knowing ourselves.

#### Persons and the Practice of Medicine

I conclude by invoking Canguilhem's comments on the relation between the human person, society, and the practice of medicine, in order to highlight a few considerations that might help resist the ideological propensity to reduce our own lives. The priority of the concept of "person" is a criterion of good moral order within a particular culture. Arguing for and achieving a balance between the priorities and just claims of individuals and those of the common good are the ongoing tasks of the political art. Canguilhem maintains,

The concept of basic personality [understood here to be synonymous with "person"] is what makes it possible, when one is considering the coexistence of cultures, to discern the invariant factor that anchors the integration of the individual into the social whole proper to each particular culture. . . In the case of basic personality, the function of intelligibility it assumes is thought to imply a refusal to put the schema of cultures into perspective from the privileged vantage point of one culture. (Canguilhem 1994a: 83)

Conversely, the modern imposition of the social whole upon the atomized individual makes him a subordinate part, valued only for his contribution to the larger structure.<sup>24</sup>

Persons may not only question the purposes of society, but may be

<sup>24</sup> Canguilhem criticizes Marcel Prenant, who eschews personality (VR: 172).

called to defend themselves against the incursions of an activist social "medicine." Proponents of "social engineering" seek not only to remedy social ills, but to introduce their own version of what constitutes the "normal" human, and whatever means that must be employed to bring the majority of individuals up to this standard. There is irony in the preceding statement; Canguilhem is appreciative of G. K. Chesterton's description of this reformist "sophism" (NP: 257-58).

The task of rational reflection upon human needs is a challenge for healthy and diseased individuals alike (VR: 378-80). Our sciences and our techniques, as well as our practice of medicine, reflect our often inchoate philosophical anthropologies. There is an inherent tension between philosophy and the values to which many of our institutional practices are committed. Canguilhem anticipates our present challenges, in which theoretical differences are amplified into practical opposition. He states:

Insofar as philosophy is the search for a meaning of life (a justification of life that is neither pure living nor even the will to live but *savoir-vivre*, knowledge of what it is to live), it enters into competition and occasionally conflict with political and religious institutions, which are collective systems for organizing human interests. (VR: 380)

The Socratic injunction endures: we are to know the life we lead, and the end for which we strive. We are also to know why certain kinds of life alterations are unworthy of being chosen for themselves.

The point here is that if the focus on genuinely therapeutic ends is defended, the truly scientific foundation for the medical art is more likely to be preserved. Canguilhem proposes a definition of medicine as "an evolving synthesis of applied sciences." He is similar to Descartes in at least one respect: he disagrees with those who think that theory holds priority over practice, or that there is a loss of theoretical dignity when knowledge is applied as in medicine. "Medicine is the science of the limits of the powers that the other sciences claim to confer upon it" (emphasis added, VR: 153). The limits for medicine consist primarily in the necessities given by nature, rather than the constraints attending our asyet-undeveloped techniques. "

<sup>25</sup> Canguilhem approvingly cites Merleau-Ponty's approbation of Descartes in Merleau-Ponty's *The Visible and the Invisible*: "The Cartesian idea of the human body as human *non-closed*—open inasmuch as governed by thought—is perhaps the most profound idea of the union of the soul and the body" (Merleau-Ponty cited in Canguilhem 2012: 50-51).

<sup>26</sup> At the aforementioned December 2015 International Summit on Human Gene

Medicine preserves its own inherent identity and avoids ideology when it recognizes the true form of its object. Medicine draws from various sciences whose internal form and limits are respected as they are employed in a practical art; in Canguilhem's own words, medicine is a synthesis

insofar as its object, whose interrogative presence is suspended by methodological choice, nevertheless remains present. That object has a human form, that of a living individual who is neither the author nor the master of his own life and who must, in order to live, sometimes rely on a mediator. However complex or artificial contemporary medicine's mediation may be—whether technical, scientific, economic, or social, and however long the dialogue between doctor and patient is suspect, the resolve to provide effective treatment, which legitimates medical practice, is based on a particular modality of life, namely, human individuality. In the physician's epistemological subconscious, medicine is truly a synthesis because, to an ever-increasing degree, it applies science to the task of preserving the fragile unity of the living human individual (emphasis added; VR: 156-67).

The awareness that human beings have the potential to visit evil on one another leads Canguilhem to propose moral constraints on the freedom afforded to human subjects in both normal and diseased states. Life is the basis for moral boundaries; affirming the presence of human life is the point of departure for all other concerns about human pathology on the personal and political levels. Only human beings in their free acts, not disease in itself, can ultimately thwart life in its aspirations for meaning and fulfillment

Editing, consensus among the roughly 500 scientists and policymakers present was to proceed with somatic cell gene editing using technologies such as CRISPR Cas9 for possible clinical applications, and to refrain from germline cell editing primarily for practical risks of potential harms introduced into germ cell lines, though this latter self-imposed restraint would be revisited as techniques improve. The only definite prohibition issued—albeit without explanation or justification—was that "if, in the process of research, early human embryos or germline cells undergo gene editing, the modified cells should not be used to establish a pregnancy" (Olson 2015: 6).

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