3 *Medical Progress as Becoming Free*

The notion that increased scientific knowledge is what drives progress persists in contemporary medicine. While working on this book, I received an email directed to the McGill University community in which the Principal and Vice-Chancellor wrote as follows:

> As we continue to tackle [the SARS-CoV-2] pandemic, our best arm is knowledge: acquiring knowledge and sharing it [.] And [let's] find a ray of hope in the words of [Steven] Pinker: "There is no limit to the betterments we can attain if we continue to apply knowledge to enhance human flourishing."[1]

This confidence in our ability to translate knowledge into human flourishing notwithstanding, in the latter half of the twentieth century, the conceptual relationships between progress, knowledge, and well-being were increasingly probed. This chapter begins by returning to a key moment for conceptions of medical progress in the context of civil rights movements when a new awareness of the insufficiencies of medical progress as "merely" scientific knowledge gains led to a sustained interest in knowledge that was empowering for patients. Amid the growing numbers of people who challenged the focus on scientific progress, many turned to freedom as a new concept for grounding medical progress. At times, this went together with more holistic views of personhood and health and the desire to put self-determination at the heart of theories of progress. Other, related trends acknowledged the potential contradictions between freedom and progress head-on and argued that taking individual freedom seriously meant challenging traditional, scientific/technological forms of medical progress. The chapter concludes with a detailed examination of the most recent instances in which

[1] Suzanne Fortier, "Message to the McGill Community Regarding COVID-19," April 29, 2020.

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technological progress is presented as being highly compatible with personal freedom. To that end, I discuss the ways in which digital medicine promises to empower and liberate patients. As we shall see, the recent emphasis on digital empowerment revives old debates about the multidimensionality of health and progress.

Before I proceed, a word about terminology is in order. Freedom is a term that relates to an array of notions about which there is a vast literature, including autonomy, self-determination, empowerment, and liberty. In what follows, I pay attention to the specific context in which such terms are used, while retaining a classic distinction between two kinds of liberty as a useful conceptual framework for navigating the terminology and concepts that come into play here.[2] These are negative liberty, in the sense of a realm in which individuals can act unobstructed, and positive liberty, associated with self-determination and the power to exercise control over one's life. Negative freedom has been associated with the absence of barriers and called an "opportunity concept" that refers back to available options, whether one can exercise them or not.[3] The notion of positive freedom is characterized by the claim that the lack of impediments to action is never a sufficient condition for freedom. Rather, it is an "exercise concept," associated with individuals' ability and power to act, whether or not they are in charge of their lives, and whether they are able to accomplish what they aspire to do.[4] Positive freedom might, therefore, be hindered by a lack of resources, or internal, psychological barriers, or outside interference. Autonomy, in a minimal sense, is precisely this kind of self-determination, which is choosing to do what one wants to do, while in more demanding conceptions of autonomy, such as Kant's version, the notion of reflective and responsible choosing is built into the idea of choice.

These distinctions are important as the terminology of freedom in Western medicine possesses a range of meanings. For example, respect for patient autonomy is taught to medical students as one of the four principles of medical ethics, along with justice, beneficence,

[2] Isaiah Berlin formulated this distinction in his essay "Two Concepts of Liberty" (1958).

[3] Charles Taylor, "What's Wrong with Negative Liberty," in *The Idea of Freedom: Essays in Honour of Isaiah Berlin*, ed. Alan Ryan (Oxford: Oxford University Press, 1979), p. 177.

[4] Ibid.

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and non-maleficence.[5] In medical ethics, this principle is thought primarily binding on healthcare providers and has given rise to a range of practices such as the facilitation of choice, the doctrine of informed consent, respect for privacy, and assessments of mental competency. According to Ruth Faden and Thomas Beauchamp, autonomy in a medical context is identified with several discrete ideas, including privacy, self-mastery, choosing freely, choosing one's own moral position, and accepting responsibility for one's choices.[6] In order to make sense of this variety, I retain the above distinctions regarding positive and negative freedom and return to how different theories of progress express particular visions of personhood.

3.1 From Technical Knowledge Gains to "Moral Knowing"

In the Introduction and Chapter 1 of this book, I summarized how progress was often associated with a particular logic and a set of interconnected changes, for example that technological innovation leads to material welfare and the establishment of more rational forms of social and political organization. Individual freedom is at the heart of these linkages. The Enlightenment portrayal of the mutually reinforcing relationship between the progress of knowledge and negative freedom is one in which the ultimate objective of progress is to increase individual freedom. But individual freedom to think and create was also at the origin of knowledge gains. Being free from constraints was thus the precondition for as well as the objective of progress, and technology was central to this narrative. It is possible to argue that the very notion of technology is unintelligible without taking into account the broader context of the faith in progress and commitment to humanity's self-liberation through its progressive dominance of the natural world. As we saw in Chapter 1, historically speaking, the arts were not perceived as exalting human capabilities and freedoms, as much as imitating nature, which was itself divine. However, with the rise of the modern idea of progress, a particular notion of free, self-development through technology arose. The

[5] Tom Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 7th ed. (Oxford: Oxford University Press, 2013), pp. 101–49.
[6] Ruth Faden, Thomas Beauchamp, and Nancy King, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986), p. 7.

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removal of external constraints on the possibilities for human control amounted to a conceptual revolution in which each particular technology is part of humanity's broader development toward freedom and self-mastery.[7] According to these assumptions, unfettered, rational inquiry into the world is what leads to truth, progress, health, and further freedoms.

In medicine, the relationship between ideas of freedom and progress has a distinct history, even as it has been affected by the broadly liberal premises outlined above. As we have seen, by the end of the nineteenth century, the typical physician–patient relationship was a paternalistic one, in which most patients willingly subjected themselves to the authority of the physician. It was also a fiduciary relationship, governed not by market principles but by the physician's duty to promote the patient's well-being. Various nineteenth-century developments such as the germ theory of disease led to a shift away from the patient's perspective by focusing on increasingly specialized processes within the body and physicians' interpretations of those processes. Nevertheless, the notion that the consent of the subject was important for medical intervention was already present at the turn of the century and gained immeasurably in international ethical reflection following World War II and the Nuremberg Code. The emphasis on individual choice within the nascent discipline of bioethics can itself be seen as a reaction against Nazi eugenic rhetoric and practices. In Chapter 2, I traced how the 1950s "reveled in the progress of medicine" and that the medical advances of the time were seen as "undiluted goods."[8] It was also at this time that the perceived link between doing science in a democracy – the "free" way of doing science, as opposed to science under fascism – and its success solidified. To be sure, portraying Western science and freedom as synonymous glossed over the fact that citizens of democracies were not equally free and did not benefit equally from scientific results and that the commitment to scientific freedom in the West could be in tension with the aim of

[7] Arthur M. Melzer, "The Problem with the 'Problem of Technology,'" in *Technology in the Western Political Tradition*, eds. Arthur M. Melzer, Jerry Weinberger, and M. Richard Zinman (Ithaca, NY: Cornell University Press, 1993), pp. 298–99.

[8] Albert R. Jonsen, *The Birth of Bioethics* (Oxford: Oxford University Press, 2003), p. 12.

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achieving global equality.[9] Nevertheless, the perception of "scientific freedom" as both apolitical and morally superior was a crucial part of the self-definition of Western science during the Cold War.

These mental preconditions notwithstanding, in the 1960s and 1970s, a new understanding of the relationship between medical progress and freedom developed. One reason was that patients were struggling on various fronts for freedom from what was increasingly perceived as the tyranny of technology. New procedures for heart surgery and insufficient or damaging treatments for mental illness were just two of the issues that were hotly debated in terms of their effects on patient well-being and medical progress more generally. The ethos of medical ethics of the time has been characterized as a general attempt to reclaim human values from ever-encroaching technology and a materialistic worldview.[10] During this time, the harmony between increased scientific medical knowledge and the possibilities of patient self-realization was increasingly scrutinized. In essence, a slow accumulation of concerns about the ramifications and ambiguities of scientific progress merged with the emerging concerns of bioethics, and the redefinition of progress was central to that endeavor.

This mood was reflected in various conferences and publications of the period. In 1960, an event entitled "Great Issues of Conscience in Modern Medicine," held at Dartmouth College in New Hampshire, aspired to pry apart the tendency to equate scientific progress with ethical advances.[11] At stake in this reexamination of progress were not simply questions of life and death, but rather what kind of survival and what kind of future? Instead of being seen as fundamentally protected from the "dark side" of scientific knowledge associated with the advent of the atomic era, it became increasingly clear that unbridled advances in medical knowledge and possibilities of intervention had their own drawbacks and even potentially devastating consequences.

[9] See Audra J. Wolfe, *Freedom's Laboratory: The Cold War Struggle for the Soul of Science* (Baltimore: Johns Hopkins University Press, 2018).

[10] Alfred I. Tauber, "Historical and Philosophical Reflections on Patient Autonomy," *Health Care Analysis*, 9 (2001), 303.

[11] "Opening Assembly: Selections from the Addresses and Panel Discussions of the Convocation, The Dartmouth Convocation on Great Issues of Conscience in Modern Medicine, 8–10 September 1960," *Dartmouth Alumni Magazine* (1960), https://archive.dartmouthalumnimagazine.com/article/1960/11/1/opening-assembly.

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Another conference on "Man and his Future," held in London in 1962, cautioned that the world had been thoroughly unprepared for the ethical and political ramifications of nuclear power; now, recent progress in biological research posed similar risks to nearly every valued aspect of human life.[12] The first human heart transplant in 1967 was followed by sustained reflections on the extent to which increased possibilities of intervention and scientific gains were accompanied by loss and ambiguities. Observers emphasized that all discussions of medical progress need to engage with the question of being human, namely what is it about human life that is or should remain constant and inviolable, and what is subject to change?[13]

By the end of the 1960s, the moral problems of medicine were competing with the public focus on the benefits of scientific progress. Rather than welcoming unequivocally new kinds of scientific knowledge, there was a perceived need for a thicker, more ethically articulated concept of progress. In a widely read book written in 1971, *Bioethics: Bridge to the Future*, Van Rensselaer Potter, a biochemist and bioethicist, described the idea of progress as moving through three roughly chronological stages – a religious, a materialistic, and a scientific-philosophic one – and argued that wisdom or the knowledge of how to balance scientific knowledge with other kinds of knowledge is "moral knowledge" and the "most important of all."[14] One result of these reflections was more emphasis on freedom's positive dimension and the importance of moral deliberation for understanding how to manage scientific advances. The philosopher who had done the most to explore the links between self-determination, reason, and morality, Immanuel Kant, was duly invoked to supplement existing accounts of freedom. In 1966, at a conference in Oregon entitled "The Sanctity of Life," philosopher Abraham Kaplan referred back to Kantian self-determination as crucial for moral decision-making and argued that "free science" must be guided by moral autonomy.[15]

[12] *Man and His Future: A Ciba Foundation Volume*, ed. Gordon Wolstenholme (London: J. & A. Churchill Ltd., 1963), p. v.

[13] Kenneth Vaux, ed., *Who Shall Live: Medicine, Technology, Ethics*, Houston Conference on Ethics in Medicine and Technology (1968) (Philadelphia: Fortress Press, 1970), p. 151.

[14] Van Rensselaer Potter, *Bioethics: Bridge to the Future* (Englewood Cliffs, NJ: Prentice-Hall, 1971), p. 49.

[15] Abraham Kaplan, "Social Ethics and the Sanctity of Life: A Summary," in *Life or Death: Ethics and Options*, eds. Edward Shils and Daniel H. Labby (Portland, OR: Reed College, 1968), p. 164.

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By returning attention to the individual person as a moral agent, this Kantian-inspired emphasis on moral will gave discussions of progress a different emphasis. It also made clear that the availability of options, that is, negative freedom, did not always lead to patients feeling free. In Kant's theory, autonomy is linked to human dignity and the potential of human beings to realize themselves as reasonable beings. By referencing Kantian theory in this way, early bioethicists laid the groundwork for other theories that associated freedom with the practical impact of realizing one's potential. And it was the nascent bioethics movement that further articulated the connections between medical progress, personal freedom, and the ability to choose reflectively and responsibly.

3.2 The New Bioethics: Progress as Patient Autonomy

With the shift in the locus of progress from the knowledge of scientists to the knowledge of moral agents more generally, patients took on an increasingly important role in assessing whether or not progress was actually being made.[16] This shift was all the more marked since, as Eric Cassell observes, until the late 1960s a patient was not a person.[17] Prior to that era, patients were not considered agents, nor were they expected to make healthcare decisions, a task incumbent on physicians, who were perceived as more detached and rational. In discussions of the moral dimensions of progress, a recurring theme was the need to treat the patient, not as subsidiary to the disease, but as a "whole person." A seminal text, Paul Ramsey's *The Patient as Person* (1970) – one that bears a marked Kantian influence – emphasized that the physician–patient relationship is a covenant, in which healers lessen the effects of sickness, while recognizing the person's dignity and rights. For him, it was precisely the moral character of the physician–patient relationship that enabled "medical progress as a human enterprise."[18]

[16] Mark Sullivan, "The New Subjective Medicine: Taking the Patient's Point of View on Health Care and Health," *Social Science & Medicine*, 56 (2003), 1595–1604.

[17] Eric Cassell, *The Nature of Healing: The Modern Practice of Medicine* (Oxford: Oxford University Press, 2013).

[18] Paul Ramsey, *The Patient as Person: Explorations in Medical Ethics* (New Haven, CT: Yale University Press, 1970), p. 37.

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At around the same time, the view that patients' bodies had separate existences from their mental lives, as largely presumed by the sciences, became increasingly controversial. Alongside the environmental movements of the 1960s, some argued that the body could no longer be reduced to biochemical processes and genetic characteristics but should rather be seen in a more holistic, integrated perspective. Sickness was increasingly acknowledged as affecting different facets of personhood far beyond the body and suffering linked to patients' psychological and social lives. The clinical insight that – with the exception of some acute infections – all illnesses differ in their outset, course, and treatment depending on the nature of the persons who have them bolstered the idea of individualized treatments and the vision of persons as highly complex entities.[19]

A new openness to patients' emotional reactions, as well as a heightened understanding of the relationship between health and happiness, went together with assigning importance to those aspects of medical care focused on controlling symptoms and ensuring a good quality of life. Reflecting back on these developments, bioethicist Diego Gracia writes that perhaps the most important goal of bioethics was its attempt to link the idea of health with moral well-being and freedom.[20] One way in which the relationship between health and happiness was portrayed at the time was grounded in the capacity of persons to communicate what was important to them. The history of reproductive medicine, for example – the birth control pill was approved by US federal authorities in the 1960s – can be recounted within a narrative of progress toward individual autonomy. Bioethics, therefore, coalesced around the insight that respect for autonomy was an essential part of respecting patients. In this view, patients are not just bodies that can be studied and healed – no matter how benevolently – but rather persons with the capacity to choose the kind of medical progress that makes sense for them.

The desirability of choice in the medical context cannot be considered independently from wider social developments. Indeed, the notion of the freedom of the patient to choose what happens to them in care

[19] Eric Cassell, "Pain, Suffering, and the Goals of Medicine," in *The Goals of Medicine*, p. 114, and Cassell, *The Nature of Healing*, p. 115.

[20] Diego Gracia, "A Historical Perspective on the Ends of Medicine," in *The Goals of Medicine*, p. 95.

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gained importance alongside broader social movements that claimed rights and earned entitlements. More broadly, civil rights movements, including women's and disability rights, offered a hopeful vision of the future which, notwithstanding the skepticism I have mentioned about the progressive development of history, gave new energy to ideas of progress as freedom. The introduction of the principle of autonomy in medicine was, therefore, framed as a necessary corrective measure that "returned power" to patients but was also the specific result of a much broader emancipation movement that placed increasing emphasis on individual rights.[21]

Autonomy in the medical setting was both the embodiment of a social commitment to freedom and a reaction to a technological, impersonal medicine that seemed increasingly hostile to individuality. Both of these contributed to the association between patient autonomy and the need to preserve a "negative" sphere of freedom from the paternalistic physician, who traditionally attempted to claim expertise in matters that were actually best decided on by the patient. Writing in 1985, American bioethicist and physician Howard Brody suggested that the physician must, in effect, back away and stand aside, presenting different options for consideration by the patient, and thereby avoid influencing their freedom of choice.[22] Standing aside, disengagement, patients' choice: the general ethos of freedom built into these concepts meshed well with a shift in medicine's priorities toward individual responsibility for health. And it fits easily with an attitude toward medical progress that stressed the work required by individuals to attain health.

With the rise of the risk factor model in the mid-twentieth century – identifying factors in patient behavior and habits suspected of contributing to the development of a disease – the capacity for disease management shifted toward the individual. As a consequence, individual responsibility for maintaining one's health was foregrounded.[23]

[21] Claudia Wiesemann, "Das Recht auf Selbstbestimmung und das Arzt-Patient-Verhältnis aus sozialgeschichtlicher Perspektive," in *Geschichte und Ethik in der Medizin. Von den Schwierigkeiten einer Kooperation*, eds. R. Toellner and U. Wiesing (Stuttgart: Gustav Fischer, 1997), pp. 67–89.

[22] Howard Brody, "Autonomy Revisited: Progress in Medical Ethics: Discussion Paper," *Journal of the Royal Society of Medicine*, 78 (1985), 381.

[23] Martin Lengwiler and Jeannette Madarász, "Präventionsgeschichte als Kulturgeschichte der Gesundheitspolitik," in *Das präventive Selbst: Eine*

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Optimizing a personal healthy lifestyle was intimately bound up with the philosophy of neoliberalism that frames health as a personal matter, linked to individual behavioral and lifestyle choices.[24] But it also linked to a Kantian subtext, whereby knowing one's potential means liberating oneself from previously imposed boundaries. The expectation that people would manage their own health dovetailed with the emphasis on the right – and the responsibility – to make choices about their health. In the words of sociologist Nikolas Rose, in the course of the twentieth century, "[t]he very idea of health was re-figured – the will to health would not merely seek the avoidance of sickness or premature death, but would encode an optimization of one's corporeality to embrace a kind of overall 'well-being'[.]"[25] This enlarged desire for health thus became bound up with more general norms of enterprise and self-actualization and was amplified by the emergence of a rapidly growing consumer market for health. And as Rose and others have pointed out, (potential) patients seek health not because of an obvious form of coercion but because they "freely" choose to be healthy, fit, and responsible; the desire for optimization can be linked to the practical desire to know one's potential.

While not all contributions of the time depicted free choice as the fundamental principle of medical progress, the conceptual framework of bioethics nevertheless associated it with respect for persons, respect for the principle of autonomy, and the ability to do what one wants to do.[26] Emphasizing the particularity of this way of approaching freedom generally went together with reiterating the novelty of this development. That patients were encouraged to have decision-making authority over their health, including their care, could easily be framed as a marked change from preceding decades and as a necessary step in the direction of progress. Writing in 1981, medical ethicist Robert Veatch asserted that never before in the history of

Kulturgeschichte moderner Gesundheitspolitik, eds. Martin Lengwiler and Jeannette Madarász (Bielefeld: Transcript, 2010), pp. 11–28.

[24] See R. Crawford, "You Are Dangerous to Your Health: The Ideology and Politics of Victim Blaming," *International Journal of Health*, 7 (4) (1977), 663–80.

[25] Nikolas Rose, "The Politics of Life Itself," *Theory, Culture & Society*, 18 (6) (2001), 17.

[26] See Renée C. Fox, "The Evolution of American Bioethics: A Sociological Perspective," in *Social Science Perspectives on Medical Ethics*, ed. George Weisz (Dordrecht: Kluwer Academic Publishers, 1990), p. 206.

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medicine had there been any acknowledgment of the patient as a dignified agent free to participate in and exercise self-determination over medical decisions.[27]

Such readings, of course, glossed over the extent to which emphasis on the "patient as a person" could be read as a revival of ancient Greek assumptions or how the demand for more accountability from those engaged in medical/human experimentation had nineteenth-century precursors. And progress in what has been called the "era of autonomy"[28] or "autonomy-centered medicine"[29] had its own unresolved issues and tensions. One of its problems was that it privileged a formal, juridical understanding of equal individual rights as a measure of progress. Emphasis on patient choice and independence did not necessarily acknowledge the extent to which a free person depends on social arrangements. And the fact of privileging autonomy was subsequently criticized for being overzealous, in that it neglected other important principles such as justice, non-maleficence, and beneficence.[30] Those interested in tracking the high point of medicine's autonomy era generally place it in the 1970s; writing in 1985, MD Mark Siegler reflected that the "Age of Autonomy" that began in the 1960s was coming to an end.[31] But he still framed it as a "progression" whereby patients gained in freedom and would never return to the previous model of unquestioned physicians' authority.

3.3 Challenges to Negative Freedom

As the above discussion illustrates, in the 1970s, the ideal of autonomy was not overly problematized but rather taken as a given. Personal autonomy, that is, self-determination through choice, was a desirable

[27] Robert M. Veatch, "Autonomy's Temporary Triumph," *The Hastings Center Report*, (1984), 38.

[28] Pär Salander and Clare Moynihan, "Facilitating Patients' Hope Work Through Relationship: A Critique of the Discourse of Autonomy," in *Configuring Health Consumers: Health Work and the Imperative of Responsibility*, eds. Roma Harris, Nadine Wathen, and Sally Wyatt (London: Palgrave Macmillan, 2010), p. 117.

[29] Toni C. Saad, "The History of Autonomy in Medicine from Antiquity to Principlism," *Medicine Health Care and Philosophy*, 21 (2018), 133.

[30] Charles Foster, "Autonomy Should Chair Not Rule," *The Lancet*, 375 (2010), 369.

[31] Mark Siegler, "The Progression of Medicine: From Physician Paternalism to Patient Autonomy to Bureaucratic Parsimony," *Archives of Internal Medicine*, 145 (1985), 714.

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trait for patients, that enabled them to make sense of a clinical encounter in which technology was increasingly present and to resist the unfair authority of physicians. However, in a next phase, the formal value of patients' rights was the subject of critical investigation from a number of directions at once. That patient choice trumped paternalism says nothing about the relationship of freedom to the agent's internal, psychological situation. Nor does it engage with the relational aspects of autonomy or fully explore the responsibilities that come with freedom. In the years and decades that followed, widely accepted views of patients as choice-making, independent persons integrated the notion that human beings are both socially and historically situated, as well as have emotional and psychological conditions that are important for realizing freedom. As a rule, this move toward more positive conceptions of freedom was also framed as progress.[32]

These changes also reflect modifications in the patient–physician relationship. From the 1990s, that relationship was reconceived as a "partnership"; as one observer put it, patients were now seen to have "grown up at last."[33] The importance of this shift, whereby healthcare progressively acknowledged the validity of patients' opinions about what happens to them in care, is so great that it has been described as a Copernican revolution in medical practice.[34] And while progress was central to this "revolution," it was bound up with various questions, such as: What are patients' preferred forms of medical progress? What weight should patients' values have and how should clinicians accompany them to honor these values? As we shall see, even as patient freedom became increasingly central to narratives of medical progress, there was no single way in which they were linked together.

3.3.1 *Self-Reflexiveness of Patients*

One way of reconceptualizing medical progress did so by emphasizing patients' experiences and their inner lives. Work in the 1980s by medical historians Roy Porter, Dorothy Porter, and others tried to recover how patients actually felt as their authority in the medical encounter

[32] Brody, "Progress in Medical Ethics," p. 386.
[33] A. Coulter, "Paternalism or Partnership: Patients Have Grown Up – and There's No Going Back," *British Medical Journal*, 319 (7212) (1999), 719–20.
[34] Renaldo N. Battista, "Practice Guidelines for Preventative Care: The Canadian Experience," *British Journal of General Practice*, 43 (1993), 303.

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declined.[35] These studies implied that truly capturing the "patient's view" provided a needed challenge to stories of biomedical progress. Within traditional narratives of medicine's progress, patient experience, at least in any extended, self-reflective form, had rarely been given space; now, some privileged patients were increasingly being heard.[36]

In addition to the greater emphasis by historians of medicine on patient experience, various narrative contributions by patients highlight how much suffering occurs in the context of clinical successes.[37] In doing so, these testimonials reveal the gaps and cracks in modernist, linear stories of progress. Instead of freedom, progress, and resolution, much illness experience reveals chaos, vulnerability, and ineffectiveness. Rita Charon and other contributors to narrative ethics have, therefore, argued for the importance of paying attention to patients' stories as a way of making "meaningful" progress.[38] Focusing on narratives for approaching progress also implies distinguishing between disease as a medical condition understood from the viewpoint of the practitioner and illness as a condition experienced by a patient. While disease is contained and possible to resolve, illness is broad and pervasive and can affect all aspects of patients' and families' lives.

Amid this narrative turn, the limitation of the idea of "options" or of choice as tantamount to progress was remarked on by both physicians and patients. Institutionalized practices such as informed consent aimed at respecting patient autonomy were often portrayed by patients as stressful decision-making processes, rather than opportunities to experience agency.[39] HIV and AIDS narratives, as well as accounts of forced choices – involuntary commitment and the end-of-life option to

[35] See, for example, Porter, "The Patient's View," 175–98 and Roy Porter and Dorothy Porter, *In Sickness and in Health: The British Experience, 1650–1850* (New York: Basil Blackwell, 1988).

[36] John Wiltshire, "Pathography? Medical Progress and Medical Experience from the Viewpoint of the Patient," *Southerly*, 66 (1) (2006), 27–28.

[37] Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* (West Lafayette, IN: Purdue University, 1993), p. 5.

[38] See Rita Sharon's *Narrative Medicine: Honoring the Stories of Illness* (Oxford: Oxford University Press, 2006) and Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988).

[39] See, for example, Walter M. Robinson, "The Narrative of Rescue in Pediatric Practice," in *Stories Matter: The Role of Narrative in Medical Ethics*, eds. Rita Charon and Martha Montello (New York, London: Routledge, 2002), p. 109.

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live on a machine or to die – played a prominent role in highlighting the existence of medical failures and futility in the context of ongoing technological progress. Instead of feeling free, and able to shape the process of illness as they might wish, patient accounts significantly complicate ideas about what progress in medicine means.

If patient narratives generally posited freedom and the self as located in the mind as much as the body, their authors sought to capture the importance of positive freedom by emphasizing the psychological and clinical conditions that prevent patients from doing what they want. This view of freedom, which acknowledges how difficult it is to take distance from a situation and to evaluate it critically, adds an additional dimension to the importance of a sphere of private choice.[40] The ability to find self-knowledge, and to engage in moral self-scrutiny, implies that healing illness involves more than acting according to whatever one's values happen to be in a particular moment. Progress of medicine, in this understanding, is analogous to patients' ability to understand the meaning of illness and recovery for themselves. Contributions from narrative medicine demonstrate that as ill people give up their bodies to medicine, they remain very concerned to shape their own stories. Medical sociologist Arthur Frank has framed this desire to hold on to one's own story as resistance, and therefore freedom. He writes that holding on to narrative independence is an important part of patients' self-reflectivity, which, in turn, creates an ideal against which the "progress of the body-self can be measured."[41]

3.3.2 *Relational Approaches to Autonomy and Progress in Medicine*

Beyond the fact that autonomy intersects with the moral life and sense of self of patients, other visions of progress incorporate the fact that free human beings are fundamentally dependent and deeply embedded in a social context. Further challenges to a negative view of freedom and valorization of privacy were rooted in what has been called a communitarian turn in ethics. This is associated with the concept of relational autonomy, which recognizes relational experiences as

[40] Louise Campbell, "Kant, Autonomy and Bioethics," *Ethics, Medicine and Public Health*, 3 (3) (2017), 381–92.

[41] Arthur Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995), p. 52.

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an integral component of individuality and freedom.[42] And if social relationships, dependencies, and self-trust are integral to freedom, these are particularly visible in the medical setting and have profound implications for health promotion.[43] Care-based and patient-centered approaches to medical ethics, for example, supplement older accounts of autonomy by emphasizing the importance of trust and interdependencies.[44] They also bring to the fore the tortuous path by which individuals struggle with their own moral impulses and the social contexts in which "autonomous" wishes and desires are formulated or oppressed. Autonomy, then, can be reconceived as a way to foster medical progress through non-oppressive caring relationships, and part of the task is understanding how background material, cultural, and social conditions affect health.

The implications for progress of leaving behind traditional individualistic assumptions about patient autonomy and thinking of patients in a fundamentally social and relational way are profound. Medical progress must be evaluated in relation to the extent to which medical interventions support patients' existence as an autonomous subject in meaningful ways, something that is influenced by all dimensions of their life – body, personal biography, relationships with others, social environment, and so on.[45] Given the complex conceptual links between freedom and social norms, simplistic accounts of technological medical progress are misguided. Thus, Susana Magalhães argues that the more scientific and technological progress in medicine, the more powerful and the more vulnerable we become.[46] In this reading, a reconfigured idea of progress needs to acknowledge the extent

[42] See Catriona Mackenzie and Natalie Stoljar, eds. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (New York: Oxford University Press, 2000).

[43] See Susan Sherwin, "A Relational Approach to Autonomy in Health Care," in *The Politics of Women's Health: Exploring Agency and Autonomy*, ed. Susan Sherwin (Philadelphia: Temple University Press, 1998), pp. 19–47.

[44] See M. A. Verkerk, "The Care Perspective and Autonomy," *Medicine, Health Care and Philosophy*, 4 (2001), 289–94 and C. Ells, M. R. Hunt, and J. Chambers-Evans, "Relational Autonomy as an Essential Component of Patient-Centered Care," *International Journal of Feminist Approaches to Bioethics*, 4 (2) (2011), 79–101.

[45] Françoise Baylis, Nuala P. Kenny, and Susan Sherwin, "A Relational Account of Public Health Ethics," *Public Health Ethics*, 1 (3) (2008), 196–209.

[46] Susana Magalhães, "Looking behind the Veil: Why Narrative Medicine Matters in Times of Uncertainties," in *Health Humanities for Quality of Care*

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to which vulnerability is related to power. The power of new medical technologies can inhibit people's freedom because it can interfere with individuals' ability to choose and act in ways that correspond to their goals and values. Relational autonomy theorists have pointed to the ways in which the ambivalent nature of technological progress in medicine does not necessarily enhance autonomy and the good life, but rather creates new dependencies and pressures to use technologies in the medical context.[47] Once individuals recognize the importance of social, political, and material pressures on their own decisions, a reconstructed idea of progress becomes clearer.[48] This revised vision of progress requires attending to patients in a more holistic sense, as people who must rely on others to be free, but who must also take critical distance from their surroundings to articulate their own conceptions of what a good life involves.

By expanding autonomy in this way, relational approaches have obvious synergies with visions of progress discussed in the next chapters that aim to promote equality (Chapter 4) and rely on an ecological approach to health (Epilogue).[49] Environmental barriers to autonomy, unjust social conditions, and power relationships should all factor into accounts of medical progress. But relational autonomy also provides the theoretical insights for understanding why social and ecological approaches to health need not diminish patient autonomy, but rather enhance it, and how this is linked to better health outcomes. Progress, in this view, is never complete since self-definition is an open-ended process of reflection and revision. An autonomous self is never finalized, but rather constantly being redefined and developed alongside others. Just as we are vulnerable to illness and death throughout our lives, finding self-respect and self-trust in the healthcare context is an ongoing, never-ending process.[50]

in Times of COVID-19, eds. Maria Giulia Marini and Jonathan McFarland (Cham: Springer, 2022), pp. 25–36.

[47] Birgit Beck, "Infantilisation through Technology," in *Technology, Anthropology, and Dimensions of Responsibility*, eds. Birgit Beck and Michael Kühler (Stuttgart: J. B. Metzler, 2020), pp. 33–44.

[48] Jennifer A. Chandler, "'Obligatory Technologies' and the Autonomy of Patients in Biomedical Ethics," *Griffith Law Review*, 20 (4) (2011), 905–30.

[49] See also Alistair Wardrope, "Relational Autonomy and the Ethics of Health Promotion," *Public Health Ethics*, 8 (1) (2015), 50–62.

[50] Janet Delgado, "Re-thinking Relational Autonomy: Challenging the Triumph of Autonomy through Vulnerability," *Bioethics Update*, 5 (2019), 60.

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3.3.3 Responsibility, Vulnerability, and Freedom

These insights from relational autonomy for progress were articulated alongside other key contributions to the intellectual history of progress and freedom in the medical context. A recurring aspect of reflections on (medical) technological progress was how the possibilities offered by technologies do not always make us freer and happier, but rather create new dependencies and multiply the reasons to be unhappy. Hans Jonas, an early contributor to bioethics, singled out medicine as the field in which the impetus for progress is particularly marked and linked this directly to human aspirations for a particular kind of freedom.[51] Yet he points out that, envisioned as a quest for unlimited, infinite progress, without a clear final goal, contemporary medicine generates new problems as fast as it resolves others.[52]

Jonas argues that striving for the ideals of progress and liberation ultimately endangers humanity because these ideals disrupt the solidarity and symbiotic relationship between the human and nonhuman natural world. Freedom of choice, for him, therefore needs to be tempered by a bioethical perspective that takes into account human survival on a finite planet and exists in close proximity to responsibility and wisdom.[53] As an action-guiding principle, Jonas proposed a new categorical imperative, namely that all should act so that the effects of that action are compatible with the permanence of genuine human life. And he refers to it as an ethics of preservation and protection that draws attention to the limitations of negative freedom and argues for a more positive view emphasizing adherence to a moral duty.

Jonas and like-minded thinkers emphasized the idea of progress in the medical context because of the way in which it combines the ontological (creating) capacities of technology and the claim that neither history nor the person has yet been fully realized. The result can be a utopian commitment to the higher person who is yet to come and the technology that can bring this about. And in its most ambitious form,

[51] Hans Jonas, "Philosophical Reflections on Experimenting with Human Subjects," *Daedalus*, 98 (2) (1969), 231. See also Giacomo Cortesi, "Hans Jonas, il progresso medico e le verità della scienza," *Humana.Mente* 7 (2008), 107–20.

[52] Hans Jonas, "Reflections on Technology, Progress, and Utopia," *Social Research*, 48 (3) (1981), 411–55.

[53] Hans Jonas, *The Imperative of Responsibility: In Search of an Ethics for the Technological Age* (Chicago: University of Chicago, 1984).

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the commitment to progress aims at bringing about a disease-free earthly paradise. In particular, if the idea of medical progress becomes the cult of technological possibility without limits, it diminishes the freedom of individuals to choose a life of their own. By reflecting on the potential tensions between technological progress and human autonomy, such arguments caution against taking an instrumental approach to human life, for example in the case of genetic enhancement or continually extending life.[54] If people are not the full moral agents of their actions – for example because they have benefited from genetic enhancement – they are not truly free.

This particular conceptualization of freedom derives from the desire to recognize human beings as responsible authors of their own lives, capable of entering into relationships with others. This approach to progress implies that authentic self-determination involves questioning the dominance of any one technique or technology no matter how useful. In attempting to think through the ramifications of the latest technology for medical progress, we must constantly ask to what extent a technology reveals the patient's holistic nature and relations between human beings. This vision of progress is affiliated with what Lucien Sève has described as progress toward an authentically human existence or progress in humanization.[55] Ultimately, it suggests that freedom and progress in the medical context are far greater than what biotechnology can provide.

3.4 Taking Autonomy Seriously: Freedom versus (Technological) Progress

While the previous pages focused on the importance of philosophically refining the concept of freedom in order to achieve progress, the following examine the practical implications of taking patients' freedom – in all its forms – seriously and the challenges this poses for conventional visions of progress. This section, therefore, highlights some of the concrete ways in which the tensions between freedom and medical progress have surfaced. In effect, the commitment to freedom, and therefore the unpredictable nature of individual and

[54] See Jürgen Habermas, *The Future of Human Nature* (Cambridge: Polity Press, 2001).

[55] Lucien Sève, *Pour une critique de la raison bioéthique* (Paris : Odile Jacob, 1994), p. 181.

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collective actions, poses a problem for any simultaneous commitment to progress.[56] Taking patient freedom seriously may go against conventional senses of medical progress – for example, choosing to refuse prescribed interventions pushes back against a technology-oriented view of progress – as well as enables unexpected forms of progress to emerge.

3.4.1 Progress and Debates at the End of Life

Debates around the end of life provide perhaps the starkest example of the potential tensions between freedom and some forms of medical progress. The Promethean ambition often associated with progress, namely the defiance and transcendence of fate, is in tension with the notion of inevitable, biological demise.[57] As mentioned earlier, death rates traditionally provided an ostensibly value-free measure for monitoring progress in medicine. Mortality reduction rates are absolutely central to narratives of medical progress and biomedical research. Yet in an era where technological progress often requires that patients or their families choose when to die, the end of life puts the tensions between freedom and progress in sharp relief.

In the course of the twentieth and twenty-first centuries, alongside an increase in the number of deaths occurring in hospitals and intensive care units, there have been a rising number of complaints about how people die. Both palliative care and assisted dying movements – as different as their methods and emphasis are – have sought to reclaim the freedom of terminally ill patients to avoid being subjected to further medical interventions.[58] Faced with death, some patients demanded freedom over their lives, including in decisions about when and how to end them. In particular, the fear of losing autonomy has been widely reported as a strong motive influencing patients to resist life-prolonging treatments. This rejection of certain kinds of medical interventions can, therefore, be framed as an expression of freedom, an act of holding on to freedom before it is taken away.

[56] See Peter Wagner, "Progress and Modernity: The Problem with Autonomy," *Sociología Histórica*, 7 (2017), 87–88.

[57] See Michael Ignatieff, "Modern Dying: The Soul Returns to the Sick Bed," *The New Republic* (26 December 1988), 32

[58] See Nina Streeck, *Jedem seinen eigenen Tod: Authentizität als ethisches Ideal am Lebensende* (Frankfurt, New York: Campus, 2020).

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These considerations occurred alongside a number of attempts to refocus progress on reducing the morbidity of aging populations rather than increasing life expectancy and emphasizing quality rather than quantity of life. In the 1960s, palliative care pioneer Cicely Saunders argued that patients should have the authority to refuse medical interventions because of quality-of-life considerations. In doing so, she sought to reorient progress away from the extension of life and toward each individual patient's journey in which they are able to adjust to and accept what is happening to them.[59] Once medicine is released from the imperative to cure, it engages in other practices that generate forms of progress that would otherwise be lost.[60] Often, progress in palliative care is identified with the prevention and relief of suffering, important goals of medicine distinct from the goal of restoring health; palliative care advocates have tried to refocus medical progress on meeting those goals.[61] Progress in this sense does not aim to find a perfect cure, but rather to meet the complex needs of ill patients, what can be thought of as helping each individual achieve the right balance for themselves in a life that will ultimately end.

If palliative care privileges a very personal understanding of progress, assisted dying – a term that comprises both physician- and patient-administered death – offers a different view of the relationship between freedom and progress. Because of its valorization of personal choice, assisted dying has been referred to as the ultimate case of prioritizing autonomy in healthcare decisions.[62] The philosophical merits of choosing to determine one's own death have ancient roots; for the stoic philosopher Seneca, suicide was the only truly free act possible and therefore ennobling. In contemporary culture suicidality is condemned, but, in some jurisdictions and for some categories of patients, assisted dying is associated with the expression of individual freedom and agency.[63] A prominent Canadian physician active in

[59] Cicely Saunders, *Living with Dying: The Management of Terminal Disease* (Oxford: Oxford University Press, 1967), pp. 54–55.
[60] See Daniel Callahan, "Modernizing Mortality: Medical Progress and the Good Society," *The Hastings Center Report*, 20 (1) (1990), 28–32.
[61] Charles F. von Gunten, "Prevent and Relieve Suffering: Professional Palliative Care," *Cancer Investigation*, 21 (6) (2003), 963–64.
[62] Joel Anderson, "Regimes of Autonomy," *Ethical Theory and Moral Practice*, 17 (3) (2014), 362.
[63] See Baril, *Undoing Suicidism* (2023).

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medical assistance in dying, Stefanie Green, frames it not as ending someone's life, but rather as empowering patients.[64] Assisted dying laws tend to portray the right to die with assistance as either a liberty or a claim right.

Some terminally ill patients highlight that it is precisely at the end of life, liberated from traditional forms of progress and the valorization of health, that they are able to achieve a kind of freedom unlike anything previously experienced. Swiss author Peter Noll, in his *Diktate über Sterben und Tod* (*In the Face of Death*, 1989 [1984]), recounts the reality of terminal cancer as providing freedom. Since life is what he holds most valuable, and it is being taken anyway, we are left with what Noll refers to as "a feeling of freedom, like a breath of fresh air. The tyranny of imagined needs – the career, the status symbols, the social pressures – becomes increasingly irrelevant, and we feel free."[65] And he notes that death forces us to think, really to think, which in turn is a part of freedom (*ein Teil der Freiheit*). In a contribution from America in a similar era, *Intoxicated by My Illness: And Other Writings on Life and Death* (1992) by Anatole Broyard, Broyard discovers a "tremendous, unprecedented freedom in being ill, a freedom (perhaps for the first time in his life) to say exactly what he wants, and to be just as crazy as he wants."[66]

Given the ways in which technological advances have shaped dying in our time, a liberation-based ethics, together with the option of palliative care, is associated with a good death.[67] And this kind of freedom and death can only be achieved by abandoning a narrative of biomedical progress. But despite calls to see the end of a life as a privileged moment of freedom and to question narratives of medical progress that relentlessly pursue health, the rights of patients to refuse life-saving treatment or to end their own lives are controversial. From a religious perspective, it is easy to imagine how technological progress

[64] Stefanie Green, *This Is Assisted Dying: A Doctor's Story of Empowering Patients at the End of Life* (New York: Scribner, 2022).

[65] Peter Noll, *In the Face of Death*, trans. Hans Noll (New York: Viking, 1989), p. 100.

[66] "Foreward," Oliver Sacks to Anatole Broyard, *Intoxicated by My Illness: And Other Writings on Life and Death* (New York: Random House, 1993), p. xiv.

[67] Meiriany Arruda Lima and Camilo Manchola-Castillo, "Bioethics, Palliative Care and Liberation: A Contribution to 'Dying Well,'" *Revista Bioética*, 29 (2) (2021), 275.

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and a related hubristic instinct, whereby individuals treat death as an occasion to express individual preferences, rather than a shared, cultural experience, can be portrayed negatively. But even without seeing death through a religious lens, observers in Western healthcare systems have drawn attention to the ways in which the reality of death often takes the form of a "wrenching choice" rather than a "deliverance of fate."[68] Another critique of the association between freedom and progress at the end of life has come from disability organizations and mental health professionals, who have highlighted the problems of permissive assisted dying laws for populations in precarious social situations. What is the freedom of the privileged to choose to die can become the oppression of the disadvantaged, who lack positive forms of freedom, such as the resources and support necessary to live well.[69] In such cases, people risk choosing an assisted death because they cannot cope with their living conditions. Even if, for some people, emancipation is associated with the freedom to choose to die, this is not the case for all, and a more nuanced depiction of progress is needed.

3.4.2 *Disability Rights and Anti-psychiatry Movements*

Traditional stories of medical progress have further been disrupted by theories of freedom within disability rights and anti-psychiatry movements. In the 1970s, the disability rights movement consolidated around the notion that prejudicial attitudes and exclusionary societal practices are far greater barriers to societal participation than the physical or mental impairments of people with disabilities.[70] In doing so, it challenged the "medical model," which views disability in terms of individual difference, deficit, or lack, and focuses on biomedical and technological progress to remedy disability. The movement critically scrutinized contemporary technological developments to address disability – cochlear implants, for example, were developed in the 1960s – that were simultaneously hailed as examples of

[68] Callahan, "Modernizing Mortality," p. 29.
[69] See Jonas-Sébastien Beaudry, "Somatic Oppression and Relational Autonomy: Revisiting Medical Aid in Dying through a Feminist Lens," *UBC Law Review*, 2 (53) (2020), 241–98.
[70] Richard K. Scotch, "Politics and Policy in the History of the Disability Rights Movement," *The Milbank Quarterly*, 67 (2) (1989), 380–400.

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medical progress.[71] In the societal model they privileged, disabilities are caused by societal norms about access and conceptions of "normal"; ideas about difference and capacity are all defined in social circumstances, and while science remains important, the most important kind of progress is the one that occurs in social institutions and ways of thinking.[72] By invoking the freedom not to have their conditions medicalized, disability activists articulated a sustained critique of traditional forms of medical progress.

Empowerment was a key concept for disability rights movements and related conceptions of progress. Justin Dart Jr., an activist who eventually became known as the Father of the Americans with Disabilities Act, outlined a "revolution of empowerment," which he describes as the elimination of obsolete thought systems and the systematic recognition that every person should live up to their potential.[73] In the decades that followed, the critique of the medical model and accompanying ideas of progress continued to be refined as the disability agenda grew internationally. Rather than portraying disability as a medical problem to be solved, disability studies highlight how we live in a world of norms and how disability cannot be grasped without understanding the norm-generating practices of a given society.[74] The agreement that reductionist tendencies of scientific-medical progress underplay the contextual complexity that creates disability was central to this movement.[75] Advocates have pointed out that health is not an objective state and that curing an organism from a

[71] See John B. Christiansen and Irene Leigh, *Cochlear Implants in Children: Ethics and Choices* (Washington, DC: Gallaudet University Press, 2002).

[72] Juliet C. Rothman, "The Challenge of Disability and Access: Reconceptualizing the Role of the Medical Model," *Journal of Social Work in Disability & Rehabilitation*, 9 (2010), 194–222.

[73] See Fred Pelka, *What We Have Done: An Oral History of the Disability Rights Movement* (Boston: University of Massachusetts Press, 2012), p. 167, and Jeanne Hayes and Elizabeth "Lisa" M. Hannold, "The Road to Empowerment: A Historical Perspective on the Medicalization of Disability," *Journal of Health and Human Services Administration*, 30 (3) (2007), 364–66.

[74] Lennard J. Davis, "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century," in *The Disabilities Studies Reader*, ed., Lennard J. Davis (New York: Routledge, 1997), p. 3.

[75] See Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, ed. Lennard J. Davis, 5th ed. (New York and London: Routledge, 2017), pp. 195–203.

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disease is not the same as establishing its health, as health refers to a complex state of affairs that includes individual experience. The Deaf community, for one, has addressed this issue by observing that Deaf individuals do not need to be "fixed" by cochlear implants.[76] The fact that many individuals are able to transform their medical disability into a cultural identity, as in the case of Deafness, and consider themselves as having good lives, is powerful evidence that not all technological breakthroughs can be equated with medical progress, nor can it be considered an unalloyed good. At the same time, the concept of empowerment remained central to narratives of disability history. In the early 2000s, buses emblazoned with the slogan "The Road to Freedom" conducted national awareness, multimedia campaigns about disability history and community.[77]

Another highly varied movement that consistently linked progress to freedom from medicine was the anti-psychiatry movement, which saw the reduction of medicalization as highly desirable and argued that mentally ill people paid a disproportionate price for the desire for medical progress.[78] In parallel to the disability rights movement, coalitions of people with mental disabilities reconceptualized liberation and progress, while also illustrating some of the ways in which freedom is in direct tension with conventional stories of progress. In the early 1970s, psychiatric survivors began to come together and call for a kind of self-determination that could not be found within the medical establishment. Psychiatric patients organized around the connecting theme of patients' rights and drew on other minority groups' use of the term "liberation" to call for their freedom from oppressive medicalization and institutions.[79] Also known as the ex-patient liberation movement, they sought to expose a system that forced patients

[76] Amelia Cooper, "Hear Me Out: Hearing Each Other for the First Time: The Implications of Cochlear Implant Activation," *Missouri Medicine*, 116 (6) (2019), 469–71.

[77] Disability Rights Education & Defense Fund, "Road to Freedom," https://dredf.org/2006/11/15/road-to-freedom/ and Gary Arnold, "ADA Legacy Tour: Get on the Bus!," Abilities.com, The Resource for the Disability Community, www.abilities.com/community/ada-bus-tour.html.

[78] See Andrew Scull, *Desperate Remedies: Psychiatry's Turbulent Quest to Cure Mental Illness* (Cambridge, MA: Harvard University Press, 2022).

[79] See Doris Zames Fleischer and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple University Press, 2011), p. 119.

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to accept treatment against their will, including involuntary institutionalization, forced drugging, electroconvulsive therapy, and – most dramatically – lobotomies.

Patient-centered histories drew attention to how oppressive so-called medical progress was for those who experienced its effects firsthand. In 1978, Judith Chamberlin published *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, an account of her mental health journey that contrasted the authoritarian way mental health services were traditionally structured with alternatives that she argued were far more suited to addressing patients' needs. If mental illness is associated with biological sources, that means the responsibility for resolving the problem lies with the individual and typically requires a pharmacological intervention, as opposed to a broader range of caring and social actions.[80] Chamberlin, together with other activists, put patient self-determination at the heart of their philosophical and political framework and emphasized the problems of a restrictive medical model of mental health, as well as those inherent in the inhumane treatment of patients. The primary objective of the mental health system, patient and activist Rae Unzicker wrote, should be to "put itself out of business."[81] A major impact of calls to resist the medical establishment in the name of freedom occurred in Italy, where a law passed in 1978 directly closed all psychiatric hospitals, though the brusqueness of the measure ended up being very hard on patients. The multifaceted public resources required to further progress by accompanying patients and providing community integration and support remained conspicuous by their absence.

3.4.3 Freedom to Refuse: Anti-vaccination Movements and Medical Progress

Before concluding this section on the potential ways in which individual freedom disrupts narratives of medical progress, I want to discuss one more example, that of anti-vaccination movements. Vaccines have been referred to as one of the greatest achievements of modern

[80] See Joseph E. Davis, *Chemically Imbalanced: Everyday Suffering, Medication, and Our Troubled Quest for Self-Mastery* (Chicago: University of Chicago Press, 2020).

[81] See Rae Unzicker, "On My Own: A Personal Journey through Madness and Re-emergence," *Psychosocial Rehabilitation Journal*, 13 (1) (1989), 76.

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medicine as well as crucial for saving lives during the COVID-19 pandemic.[82] The history of vaccines reveals significant advances in understanding disease vectors and immunology, as well as in the ability to make and distribute vaccines at scale. And yet, anti-vaccine sentiments are on the rise. Vaccine hesitancy, which is also the rejection of a particular kind of medical progress, is currently described as a major risk to global public health.[83] Indeed, it has been portrayed as precisely what is undermining general progress trends in medicine.[84]

The arguments of vaccine skeptics, to be sure, are marked by their plurality, and the shifting reasons for vaccine hesitancy were all already present since the development of vaccines. Recent studies confirm that the decision to vaccinate is a complex process, in which both cognitive and emotional factors play a role.[85] But despite this complexity, the strand of thinking that rejects vaccines in favor of individual rights and autonomy gained new prominence in recent years.

Arguments for individual liberty and against vaccines cut across political and geographical divides. Traditionally, the anti-vaccination movement has been associated with a libertarian distrust of the medical establishment. Anti-vaccination sentiments have a large overlap with support for alternative medicine broadly conceived and a certain skepticism toward conventional medicine (*Schulmedizin*) and big pharma. They are also associated with the view that science is just one way of perceiving reality, among other valid ones. Compulsory vaccination is perceived as encroaching on people's liberty and contrary to the right of parental control, ideological arguments that have remained remarkably similar over time.[86] Discussing a vaccine bill in Colorado, one parent refers to the bill as "a step toward the complete

[82] See this comment by former US Surgeon General Jerome Adams, @JeromeAdamsMD, https://twitter.com/JeromeAdamsMD/status/1711912940721299584 and his book, *Crisis and Chaos: Lessons from the Front Lines of the War against COVID-19* (Nashville, TN: Post Hill Press, 2023).

[83] The World Health Organization, "Ten Threats to Global Health in 2019," www.who.int/emergencies/ten-threats-to-global-health-in-2019.

[84] Azhar Hussain et al, "The Anti-Vaccination Movement: A Regression in Modern Medicine," *Cureus*, 10 (7) (2018), e2919.

[85] Noni E. MacDonald, SAGE Working Group on Vaccine Hesitancy, "Vaccine Hesitancy: Definition, Scope and Determinants," *Vaccine*, 33 (34) (2015), 4161–64.

[86] Rob Boddice, "Vaccination, Fear and Historical Relevance," *History Compass*, 14 (2) (2016), 71–78.

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erosion of our medical freedom."[87] The freedom they are referring to is the freedom of parents to choose whether or not to vaccinate their child, rather than being obliged to do so by medical institutions. Attributing responsibility for health to individuals and their immediate families, rather than healthcare institutions, reoccurs among those opposed to vaccines both today and in the past. It is heard in the "my body my choice" anti-vaccination slogan (originally a feminist slogan referring to women's rights to reproductive choices), the Swiss *Freiheitstrychler* (Freedom ringers), and in posters with messages like "freedom not fear," "we do not consent," and so on.

In addition to a general skepticism of conventional narratives of medical progress, anti-vaccine sentiments are associated with a more general distrust of public institutions, which emphasizes individual experience and liberty while questioning the validity of "expertise."[88] The freedom not to vaccinate is a manifestation of the more general concern not to have the government impose one specific vision of progress. But the freedom invoked by anti-vaccine advocates tends to be much less concerned with the implications of that refusal for the freedoms of others, namely the health and well-being of society at large. In most cases, the arguments in favor of freedom do not take due account of the necessary tension between different freedoms in society and the need to find a compromise between them. Neither do they acknowledge the extent to which the free person depends on social arrangements, in particular the social solidarity offered by a well-functioning health system.

Even as anti-vaccine advocates are often portrayed as opposed to medical progress, their concerns for safety and capacity to provide civic oversight have had positive effects. For example, relatively high rates of vaccine hesitancy among certain communities have shed additional light on preexisting problems of healthcare, such as institutionalized racism.[89] The existing strategic interests of various stakeholders and the legacies of colonialism have been made newly visible

[87] Cited in Arthur Allen, "How the Anti-Vaccine Movement Crept into the GOP Mainstream," *Politico*, May 27, 2019, www.politico.com/story/2019/05/27/anti-vaccine-republican-mainstream-1344955.

[88] See Maya J. Goldenberg, *Vaccine Hesitancy: Public Trust, Expertise, and the War on Science* (Pittsburgh, PA: Pittsburgh University Press, 2021).

[89] See the Wellcome Trust-funded project, *Healthy Scepticism*, www.healthyscepticism.com.

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in various large-scale vaccination campaigns.[90] The vaccine success story is, therefore, marred by imperialism and paternalism and in general reflects broader structural failures across global health. But in general, vaccination is a field in which the potential tensions between the constraints imposed on individual behavior and the well-being of all have played out. As examples of major public health issues, vaccination campaigns illustrate particularly well the tensions between different kinds of medical progress – between the freedom of individuals and the health needs of society at large, between the scientific power of the few, and the complexities that come with using that power to improve health outcomes for all.

3.5 Reclaiming Progress as Freedom

Despite the tensions and oppositions described above, and the fact that the emphasis on freedom points toward no single practice or action for medicine, the political association between freedom and progress has remained considerable. Patient autonomy remains the best-known principle of medical ethics and a widely accepted value for defining medical progress. Philosopher Somogy Varga holds that medicine's final aim is to enhance human autonomy; meanwhile, "[t]he more autonomy in medicine, the more progress" has been described as one of the main presuppositions of contemporary medicine.[91] Indeed, as a rule patient freedom is portrayed as highly compatible with medical progress. And this compatibility is a key part of the so-called "liberation mythology" that associates digitalization with both progress and patients being empowered to take control of their health.[92]

Since the early 2000s and the advent of Web 2.0, mobile devices like smartphones, tablets, and wearables have all had a significant

[90] Mosoka P. Fallah & S. Harris Ali, "When Maximizing Profit Endangers our Humanity: Vaccines and the Enduring Legacy of Colonialism during the COVID-19 Pandemic," *Studies in Political Economy*, 103 (1) (2022), 94–10.

[91] Ignass Devisch, "Progress in Medicine: Autonomy, Oughtonomy and Nudging," *Journal of Evaluation in Clinical Practice* 17 (2011), 857. See Somogy Varga, "The Aim of Medicine. Sanocentricity and the Autonomy Thesis," *Pacific Philosophical Quarterly*, 104 (4) (2023), 720–45 and Somogy Varga, *Science, Medicine, and the Aims of Inquiry* (Cambridge: Cambridge University Press, 2024).

[92] On liberation mythology, see Nicholas Carr, *Utopia Is Creepy and Other Provocations* (New York: W. W. Norton & Company, 2016).

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impact on how individuals experience and perceive health. So too have social media platforms, citizen science initiatives, and platforms such as PatientsLikeMe, HealthBoards, or WebMD, which allow patient communities to gain and share information. The digital prosumer, a term coined to show how the distinction between producers and consumers of (online) content has been fundamentally blurred, has also emerged as one uniquely able to drive progress. The health data that is continuously generated from patients' devices contains a vast amount of potentially useful knowledge. Part of the hype is linked to the accessibility and democratization of knowledge: If rapid information acquisition and knowledge sharing without geographical constraints are possible for a larger number of people, these processes can be portrayed as increasingly democratic and egalitarian and reframed as human progress.[93] While the doctor has traditionally been the gatekeeper for medical knowledge and making medical decisions, in the artificial intelligence era, this hierarchy is portrayed as having been overcome; it is possible that medical knowledge that forms the basis of decision-making will be as accessible to the patient as to the doctor.[94]

In this worldview, progress is associated with encouraging people to voluntarily undertake practices to improve their health and fitness. As one enthusiast puts it, the old thinking "My health is the responsibility of my physician" is fundamentally outdated; the new thinking is that "My health is my responsibility, *and I have the tools to manage it*" (my emphasis).[95] These "digitally engaged"[96] patients are portrayed as at the forefront of this particular type of medical progress. As depicted in the influential *Topol Review*, a report for the British National Health System on its digital strategy, individuals will increasingly generate their own health data, and AI will transform this data into clinically useful information and empower patients to manage their own health

[93] Brynjolfsson and McAfee, *The Second Machine Age*, p. 86.
[94] Xiaoxuan Liu, Pearse A. Keane, and Alastair K. Denniston, "Time to Regenerate: The Doctor in the Age of Artificial Intelligence," *Journal of the Royal Society of Medicine*, 111 (4) (2018), 115.
[95] Melanie Swan, "Health 2050: The Realization of Personalized Medicine through Crowdsourcing, the Quantified Self, and the Participatory Biocitizen," *Journal of Personalized Medicine*, 2 (2012), 108.
[96] Deborah Lupton, "The Digitally Engaged Patient: Self-Monitoring and Self-Care in the Digital Health Era," *Social Theory and Health*, 11 (3) (2013), 256–70.

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or seek appropriate support.[97] Digitalization and the deciphering of the genome are consistently portrayed as underpinning one of the most profound disruptions in medicine ever experienced. And related trends toward the decentralization of care and decision-making are consistently framed as game-changing forms of progress; the head of a major Montreal hospital, Dr. Lawrence Rosenberg, argued in a 2019 workshop that they are precisely what enable patients, for the first time ever, to take control of their health.[98]

3.5.1 Personalized, Participatory Medical Progress

Within the broader recasting of digital medicine and narratives of progress, personalized medicine plays a unique role. Personalized medicine aims to develop therapies based on individuals' unique molecular, clinical, and lifestyle information, using emerging, data-intensive means to do so. It is also the product of developments in biology that made it possible to carry out molecular analyses of and interventions in fundamental biological processes. Looking at organisms, their health and disease, through a genetic and biochemical lens, has been called a "molecular revolution" with multiple practical applications.[99] Capitalizing on this enthusiasm for a new way of framing disease, the editors of a recent book on its ethics observe that the term personalized medicine has become "the symbol of medical progress" and a label for better medical care in general.[100]

[97] *The Topol Review. Preparing the Healthcare Workforce to Deliver the Digital Future: An Independent Report on Behalf of the Secretary of State for Health and Social Care*, NHS Health Education England, February 2019, p. 47.

[98] Lawrence Rosenberg, "Disintermediation," Presentation Given at *Workshop: Medicine without Doctors? Disintermediation and Patient Agency*, 4th Workshop on the Impact of Technological Change on the Surgical Profession, May 8, 2019, Jewish General Hospital, Montréal.

[99] Michel Morange, *The Black Box of Biology: A History of the Molecular Revolution*, trans. M. Cobb (Cambridge, MA: Harvard University Press, 2020) and Robert Olby, "The Molecular Revolution in Biology," in *Companion to the History of Modern Science*, eds. G. N. Cantor et al. (London: Routledge, 1996), pp. 503–20.

[100] Jochen Vollmann, Verena Sandow, Sebastian Wäscher, and Jan Schildmann, eds., *The Ethics of Personalised Medicine: Critical Perspectives* (Farnham: Ashgate, 2015), p. 1. See also George Annas, "The Songs of Spring: Quest Myths, Metaphors, and Medical Progress," in *Ethics and the Arts*, ed. Paul Macneil (Dordrecht: Springer, 2014), p. 226.

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These references to a conceptual revolution help explain why the hyperbolic language of progress so significant it will eliminate all diseases has resurfaced in reference to molecular biology and digitization. At an event marking the completion of the first draft of the human genome, US President Bill Clinton claimed that it is now conceivable that "our children's children will know the term 'cancer' only as a constellation of stars," while British Prime Minister Tony Blair characterized this "revolution in medical science" as having implications that "far surpass even the discovery of antibiotics."[101] Advocates of personalized, also called genomic, medicine maintain that it represents revolutionary progress not just in treatment possibilities but also in how patients are empowered to take control of their health. Francis Collins, a prominent figure in genomics research in the United States, describes the success of personalized medicine as developing alongside the need for each individual to take responsibility for their own health. And he uses the language of revolution and "paradigm shift" to underscore both the novelty and the possibilities of citizens living "life to the fullest" by harnessing this new research for health.[102]

Personalized medicine capitalizes on the language of empowerment, but it gives freedom a different meaning beyond individual rights in healthcare decisions. Advances in DNA sequencing, combined with the emergence of large biobanks in the 1990s, were linked with a shift from individual choice and control to concepts such as partnership and participation.[103] As a rule, the need for a participatory approach in medicine has been persistently characterized as the extension of what honoring patient autonomy really entails. In 2015, Barack Obama launched the Precision Medicine Initiative, which aimed to inaugurate a new era of medicine as well as to empower patient-participants.[104] Specifically, patient engagement has been portrayed as driving the progress of more personalized and efficacious medical

[101] "Remarks made by the President, Tony Blair, Francis Collins, and Craig Venter," The White House, Office of the Press Secretary, June 26, 2000, www.genome.gov/10001356.

[102] Francis Collins, *The Language of Life: DNA and the Revolution in Personalized Medicine* (New York: Harper Perennial, 2011), pp. xxiv, 275.

[103] See Alessandro Blasimme and Effy Vayena, "Becoming Partners, Retaining Autonomy: Ethical Considerations on the Development of Precision Medicine," *BMC Medical Ethics*, 67 (2016), 2.

[104] The Precision Medicine Initiative, The White House, President Barack Obama, https://obamawhitehouse.archives.gov/precision-medicine.

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products. Medical progress is regularly framed as personalized, preventative medicine that relies on patient choice and participation.[105]

Participating in processes that affect one's life is a key element of positive freedom. But despite the rhetoric of participation and sharing, personalized health is associated not so much with open, representative spaces as with commodified ones. Among those who are empowered or likely to be given more opportunities by personalized medicine are those patients who are interested in their genomic data and can afford to access it. The line separating voluntary health promotion practices, individualized health states, and government and corporate strategies is increasingly blurred.[106] Powerful private actors, such as Google and genetic testing companies, also profit. The equation these companies propose between participation and empowerment serves their commercial interests, as they go on to benefit from access to valuable biomedical resources, profit from public funding, and yet are not accountable to the public.[107] Claims about empowering patients are associated with the notion of the consumer-patient, who is able to receive test results directly and make health decisions while bypassing doctors. It also creates demand, using the rhetoric of empowerment to give patients a stake in the movement itself. In doing so, the language of predictive, preventive, personalized, and participatory medicine intentionally avoids the word patient in favor of the client[108] and thereby disrupts the traditional fiduciary nature of the physician–patient relationship in which the patients' interests are paramount (in contrast to caveat emptor or buyer beware). It also shifts the responsibility for healthcare away from collective forms of freedom, as guaranteed by social and political structures, and onto individual patients.

[105] Margaret Anderson and K. Kimberly McCleary, "From Passengers to Co-pilots: Patient Roles Expand," *Science Translational Medicine*, 7 (291) (2015), 291fs25 and Matthias Orth et al., "Redefining the Role of the Physician in Laboratory Medicine in the Context of Emerging Technologies, Personalised Medicine and Patient Autonomy ('4P Medicine')," *Journal of Clinical Pathology*, 72 (3) (2019), 194.

[106] Tamar Sharon, "Self-Tracking for Health and the Quantified Self: Re-articulating Autonomy, Solidarity, and Authenticity in an Age of Personalized Healthcare," *Philosophy of Technology*, 30 (2017), 93–121.

[107] See Donna Dickenson, *Me Medicine vs. We Medicine: Reclaiming Biotechnology for the Common Good* (New York: Columbia University Press, 2013).

[108] Matthias Orth et al., "Redefining the Role of the Physician," p. 195.

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To recall, what genomic science can provide is, first, probabilistic knowledge about a patient's possible chances of being affected by various ailments and, second, information about a patient's potential response to specific treatments. The prospective empowerment of patients, therefore, must be compared with other information relevant to understanding, preventing, or treating disease and other types of choices that may be more significant with regard to health.[109] Biostatistician Melody Goodman has spoken to this issue by highlighting the way in which personalized medicine does not fully capture the social determinants of health and noting that, in fact, zip codes are a better predictor of health than genetic codes.[110] A further problem from the perspective of patient autonomy is how incidental findings should be managed and whether the patient should be informed about them.[111] This is linked to the fact that patients tend to have very little control over what kinds of personal data are collected and how they go on to be used, for example by insurance companies.

Genomic technologies capitalize on the language of medical progress in several ways. The association between personalized medicine, the self-actualizing individual, and the "personalism" of a caring physician–patient relationship offers a rhetorically powerful view of progress. Personalized medicine in the sense of genomic medicine has profited from this vagueness, without offering a clear commitment to holistic, person-centered care.[112] Another way in which genomic technologies have been associated with an idea of progress is through their aim to provide both high-quality individualized care and increasingly accessible health services for all. In a special issue devoted to personalized medicine, the President of ETH Zürich Lino Guzzella claims that "medicine for all" is soon going to become a reality and links

[109] Eric Juengst, Michael A. Flatt, and Richard A. Settersten, Jr., "Personalized Genomic Medicine and the Rhetoric of Empowerment," *Hastings Center Report*, 42 (5) (2012), 35.

[110] Melody Goodman, cited in "Zip Code Better Predictor of Health than Genetic Code," News, Harvard T. H. Chan School of Public Health, 4 August 2014, www.hsph.harvard.edu/news/features/zip-code-better-predictor-of-health-than-genetic-code/.

[111] G. de Wert et al., "Opportunistic Genomic Screening. Recommendations of the European Society of Human Genetics," *European Journal of Human Genetics*, 29 (2021), 365–77.

[112] See Miriam Solomon, *Making Medical Knowledge* (Oxford: Oxford University Press, 2016).

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personalized medicine with the impressive medical progress of the past decades.[113] The twin promise of better health outcomes and lower costs recurs in the current enthusiasm for digital technologies and for genomics in particular. Yet just how accessible these tools are remains to be seen; so far, the increased costs associated with personalized medicine are considerable.[114]

3.5.2 Human Enhancement as Progress and Liberation

One further domain that is portrayed as the final frontier of the liberation of human beings through progress in medicine is human enhancement. Enhancement refers to a range of technological (i.e., cosmetic/plastic surgery), psychopharmaceutical, or genomic interventions to improve human beings, allowing them to function beyond a normal range, and therefore can blur with personalized medicine.[115] Preventative and enhancing medicine have been described as inseparable, and both are associated with the rise of personalized medicine and the existence of active and informed healthcare consumers who want to exercise choice in the medical context. Both enhancement and personalized medicine emphasize the shift within the physician–patient relationship toward the patient-consumer, the ways in which digitalization facilitates this shift and associated freedoms.

At the simplest level, to enhance something is to improve it; the concept of enhancement thus contains in itself the notion of progress. Like many forms of medical progress, enhancement explicitly aspires to overcome limitations, in this case, those associated with human biology. It is possible to argue that enhancement is the logical extension of medical progress itself, which is constantly aggrandizing medicine's traditional therapeutic mandate.[116] As discussed previously, medical

[113] "Medizin Nach Mass: Mit Personalisierter Medizin zur Gesundheit von Morgen," *ETH Zürich Globe*, 1 (2018), 3.

[114] Elvio Baccarini, "Personalized Medicine, Justice and Equality," in N. Bodiroga-Vukobrat et al., eds., *Personalized Medicine in Health Care Systems* (Switzerland: Springer Nature, 2019), pp. 137–47.

[115] See Philip Brey, "Human Enhancement and Personal Identity," in *New Waves in Philosophy of Technology*, eds. Jan Kyrre Berg Olsen, Evan Selinger, and Søren Riis (New York: Palgrave Macmillan, 2008), pp. 169–85.

[116] Ulrich Körtner, "The Challenge of Genetic Engineering to Medical Anthropology and Ethics," *Human Reproduction and Genetic Ethics*, 7 (1) (2001), 22.

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progress is responsible for determining what counts as normal human functioning; without the insights of bacteriology, "normal" human life span and health look different from what they are now. Some have associated precisely the blurring between therapy and enhancement with the implicit goals of biomedical progress, namely a definitive understanding of the causes of disease, as well as the indefinite extension of human life.[117]

The concept of freedom is inevitably front and center in the debate over human enhancement, which has been characterized as essentially a debate about human freedom.[118] This focus on freedom has been associated with a perceived harmony between choosing among different options and positive freedom in the sense of a self-ruled life. Bioethicist John Harris, for example, has argued that enhancement will allow humans to live more freely because they will not fear illness, pain, and premature death to the same extent; it will therefore allow them more control over their bodies and their destinies.[119] Being free can be equated with using technology to do what humans have done throughout history, namely to try and improve/enhance their lives using different means.

Proponents of enhancement have argued, furthermore, that the rationale for enhancement harmonizes the requirements of freedom and justice.[120] Harris, for one, argues that we are obligated to pursue human enhancement, as he sees biotechnological means as simply the most recent in a long series that human beings have used to improve themselves.[121] If arguments in favor of enhancement typically rely on an understanding of freedom as increasing human control, the close association they posit between freedom and control elides an easy

[117] However, for a distinction between enhancement and therapy, see Robert Sparrow, "Better than Men? Sex and the Therapy/Enhancement distinction," *Kennedy Institute of Ethics Journal*, 20 (2) (2010), 115–44.

[118] Ramez Nam, *More than Human: Embracing the Promise of Biological Enhancement* (New York: Broadway Books, 2005), p. 9 and Jan-Christoph Heilinger and Katja Crone, "Human Freedom and Enhancement," *Medicine Health Care and Philosophy*, 17 (1) (2014), 13–21

[119] John Harris, *Enhancing Evolution: The Ethical Case for Making Better People* (Princeton, NJ: Princeton University Press, 2011).

[120] Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Winkler, *From Chance to Choice: Genetics and Justice* (Cambridge: Cambridge University Press, 2000).

[121] John Harris, *Enhancing Evolution*, p. 9.

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distinction with justice. In general, advances in medicine have made addressing what was previously considered "natural" a requirement of justice. As Martha Nussbaum has clarified, many things that may previously have been considered a given now appear as things that people can change and may even have an obligation to change.[122]

At the same time, there are descriptive and normative reasons to challenge the notion that the enhancement of individuals will be empowering for all patients. For example, gene editing that enables parents to make important decisions regarding their children's health for enhancement purposes remains controversial. In this case, the perceived difference between therapy and enhancement is crucial in the minds of the public; 83 percent of citizens in a US public opinion survey found that genetic modification to make a baby smarter would be "taking medical advances too far."[123] Furthermore, implying that health exists in a stable way, and that attaining it is our shared goal, mistakenly assumes that one particular kind of medical progress can achieve it. In practice, however, if the specific technologies of enhancement are used to assess progress toward a purportedly stable goal, they can narrow our understanding of what means we have to achieve health. Bioethicist and disability studies professor Rosemarie Garland-Thomson, reflecting on the dangers of devalorizing variations between humans through enhancement techniques, calls, not for upgrading humans to fit better with the world, but rather for improving the world so that it can be more welcoming to all human experiences. This, she observes, could be done by using insights from disability culture, theories of justice, and inclusive technologies to make a shared world welcoming to the widest range of users.[124]

Other critics of enhancement point out that the freedom of some is not consistent with justice for all. When deployed in existing, unequal social contexts, enhancements are more likely to exacerbate rather than

[122] Martha Nussbaum, "Review of Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Winkler, *From Chance to Choice* (2000)," in *Philosophical Interventions: Reviews 1986–2011* (Oxford: Oxford University Press, 2012), pp. 234–45.

[123] Antonio Regalado, "Engineering the Perfect Baby," *MIT Technology Review*, 118 (3) (2015), 26–33.

[124] Rosemarie Garland-Thomson, "Welcoming the Unexpected," in *Human Flourishing in an Age of Gene Editing*, ed. Erik Parens and Josephine Johnston (Oxford: Oxford University Press, 2019).

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alleviate social injustices.[125] Those who can initially afford these technologies will see their privileges amplified by enhancements, whether physical, cognitive, or psychological, and existing social inequalities will increase. Neither is it a given that today's major health problems are being well served by proposed enhancement technologies. If human enhancement is a question of improving some aspects of health with expensive, scarce technologies, it has very little relevance to the health needs of the general population. Health goals that are achievable in the present may be undermined when funds are spent on a future health goal, the ramifications of which are unclear and potentially give rise to unwanted results. Ultimately, defining what counts as progress and liberation remains a question of power.

3.6 Conclusion

Since roughly the 1970s, ideas about freedom and medical progress are bound up together in new ways. The ambiguities inherent in increases in scientific medical knowledge led to the development of a new idea of progress that shifted in focus and content. Against the notion of a technologically deterministic idea of fate, and of paternalistic physicians deciding what was best for their patients, progress was henceforth connected to the idea of patients as persons, with their own values and choices. This development dovetailed with the broader emphasis on individual rights in the context of various emancipation movements.

However, freedom played a fluid and at times unruly role in discussions of progress. Part of this is due to the fact that there is no single understanding of the relationship between positive and negative forms of freedom, and arguments for freedom were used both for and against technological forms of medical progress. The initial move to (re)install the patient at the center of healthcare, and the birth of bioethics that paid due attention to patient beliefs, was marked by optimism. In subsequent years, a number of challenges to the predominance of individual rights in healthcare came from various sources. From the philosophical side, a new emphasis on the relationality of

[125] Tamara Garcia and Ronald Sandler, "Enhancing Justice?," *Ethics and Emerging Technologies*, ed. R. L. Sandler (London: Palgrave Macmillan, 2014).

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autonomy questioned whether freedom could be honored with the provision of treatment options or whether it needed to be rethought much more collectively. Others questioned whether authentic freedom could even be obtained in a cultural mindset that privileged technological progress. Further, deep-seated challenges came from those who saw the affirmation of freedom as their right to oppose various forms of progress.

Yet the Enlightenment dream of an uncomplicated relationship between freedom and progress continues in many instances to thrive. Digital medicine is full of references to how particular technologies and applications will liberate patients and empower them through their own participation in medical treatment. Pushed to the extreme, these assumptions about freedom point in the direction of human enhancement and genetic engineering and a new view of selfhood for the digital age. The most sustained critiques of these particular views of progress emphasize the role of the state and society in ensuring the self-determination of their citizens. In the next Chapter, I want to turn to a particular form of this critique, one that emphasizes health in a community and argues that not freedom, but rather justice is the correct concept to anchor theories of progress in medicine.

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