



Post-Patienthood. Health Risks and the Reflexivity of Self-Embodiment

Abstract: By discussing social and technological developments in the system of biomedicine, the article aims to postulate an identity pattern in which human embodiment is inscribed in the context of advanced biotechnologies, especially genetics and genomics. The concept of post-patienthood refers to individual identity as a construct that relates the person's present medical condition to a range of possible future scenarios, each formulated on the basis of genetic susceptibility to a particular disease. The post-patient, therefore, is neither healthy nor ill, and the present medical condition could be irrelevant to their sense of embodiment.

Keywords: biomedicalization, embodiment, patient, risk, genetics

Introduction

The notion of patienthood is usually defined by postulating a relationship between individual agency and systems of institutionalized healthcare. It is a type of individual identity which denotes the reflexive individual whose lived experiences are given meaning in the context of coping with a medical condition that requires professional diagnoses and management. Not surprisingly, patienthood is an existential condition of being thrown into “an alternate universe within the world of the living, focused on the bodily problems that interrupt and that can, ultimately, end life.”¹

Following the development of genetics, genomics, and genetic counseling, this article postulates a pattern of individual identity in which human embodiment is given sense in the context of diagnosis and management of multifactorial medical conditions.² As opposed to patienthood, which focuses on the actual presence of

1. Wendy Simonds, *Hospital Land USA. Sociological Adventures in Medicalization* (New York and London: Routledge, 2017), 15.

2. Multifactorial medical conditions are caused by the interaction of genetic and environmental components. This pattern of gene-environment interaction is most evident in the case of chronic disorders, especially cancer. See: Siddhartha Mukherjee, *The Emperor of All Maladies. A Biography of Cancer* (New York: Scribner, 2010).

medical conditions and their role in the individual's embodiment, the postulated nation of post-patienthood refers to the temporality of one's body understood as a continuum of past, present, future embodiments. Hence, post-patienthood is a form of embodied identity that relates the individual's actual physical condition to a range of possible future scenarios, each calculated on the basis of one's genetic susceptibility to a particular disease. Both genetic and environmental determinants (e.g., dietary choices, one's socioeconomic status, or medical literacy) are here considered in terms of individual risk factors used to predict the person's vulnerability in the future.

Given the probabilistic character of the hereditary vulnerabilities, the most conspicuous element of post-patienthood is its overtly temporal character. The post-patient resides in a future understood as a range of possible future scenarios calculated on the basis of an interaction between one's genetic susceptibility and environmental risk factors. As a consequence, the post-patient's reflexivity is routine of risk calculation and risk management in which their body becomes a project in the process of becoming.

This article pays its intellectual debts to three methodologies that investigate into social and cultural frameworks of health and illness. Our idea of post-patienthood is given its structural underpinnings in the theories of "epidemiologic transition" and "biomedicalization" which explain the role of chronic diseases in the construction of society, and discuss the extensive penetration of popular knowledge, mass media, and educational practices by sophisticated medical technologies. On the other hand, the agential element of post-patienthood is discussed in the context of social and cultural theories of risk. It refers to activities undertaken by post-patients to reflexively colonize the uncertain future by means of risk prioritization and uncertainty reduction.

The Structural Conditions of Post-Patienthood

Our notion of post-patienthood is rooted in structural conditions of late modernity, especially in social and technological transformations associated with epidemiologic transition and biomedicalization. The former tendency has resulted in the implementation of life-long disease prevention and management into the mainstream of social life. Economic stability and longevity of late modern populations have introduced chronic disease management as an indispensable element of individuals' daily routines, relating their actual medical condition to the supervision of long-term physical and mental consequences.³ Biomedicaliza-

3. Despite its considerable potential for generating public fears, the COVID-19 pandemic has proven to be a merely temporal aberration in the otherwise steady tendency towards the increase

tion, in turn, has paved the way for colonization of social life by medical science and technology, postulating the formation of collective and individual identities on the basis of biological qualities, as in the case of technoscientific identities in patients with multifactorial genetic disorders.⁴

Illness is an inevitable element of the human condition, and diseases are densely interwoven into the fabric of social experiences, disrupting individual biographies as well as societies' overall prosperity. However, the actual distribution of medical conditions in a given population is a historically changeable figure, which is closely related to technological and economic progress and its role in the elimination of basic risks factors, such as poor sanitary conditions, unreliable food supply, or overpopulation. This phenomenon is explained by the notion of "epidemiologic transition" which is concerned with the determining role of modernization processes in the prevalence of certain types of diseases.⁵ The process epidemiologic transition is observed as a shift from societies in which infectious and parasitic diseases are the main sources of health-related concerns to societies whose major source of health anxieties is the increasing prevalence of chronic and degenerative diseases, such as cancer, cardiovascular diseases, or autoinflammatory diseases.

Phenomenologically, the process of epidemiologic transition removes a number of imminent and observable dangers from the spectrum of everyday experiences as it focuses the society's attention on imperceptible health risk factors (e.g., carcinogenic substances in food, maladaptive gene mutations) and chronic medical conditions that require a technologically sophisticated diagnosis and long-term treatment. As a result, fear has lost its tangible character and now it lurks at the shadowy hinterlands of human experience, chief among which is the genotype. In a way, the epidemiologic transition socializes us to live in a culture of risk that motivates individuals to "regard fear as a default response to life itself."⁶ Our current preoccupations with health risks have been given a less ostentatious form, especially when compared to perils of living in pre-transition societies where

in number premature deaths caused by chronic medical conditions, especially cancer and heart disease. See: Freddie Bray, Mathieu Laversanne, Elisabeth Weiderpass, and Isabelle Soerjomataram, "The Ever-increasing Importance of Cancer as a Leading Cause of Premature Death Worldwide," *Cancer*, vol. 127, no. 16 (2021): 3029–3030.

4. Adele E. Clarke, Janet K. Shim, Sara Shostak, Alondra Nelson, "Biomedicalising Genetic Health, Diseases and Identities," in *Handbook of Genetics and Society Mapping the New Genomic Era*, ed. Paul Atkinson, Peter Glasner, and Margaret Lock (London and New York: Routledge, 2009).

5. Abdel R. Omran, "The Epidemiologic Transition. A Theory of the Epidemiology of Population Change," *The Millbank Memorial Fund Quarterly*, vol. 49, no. 4 (1971): 509–538.

6. Frank Furedi, *The Culture of Fear Revisited* (London: Continuum, 2006), ix.

“death was on display everywhere, to the point of banality.”⁷ Once represented as the omnipresent Grim Reaper, the banality of death is nowadays given a more civilized form. It could be a biopsy, or a genetic susceptibility test offered to an individual facing the risk of cancer.

The life-long management of health risk factors requires a model of biomedicine that goes well beyond the institutionalized system of healthcare. In this context, biomedicine becomes a social system that permeates the mainstream of social life, producing an all-encompassing network of health and wellbeing practices. Thusly understood, the biomedicalization of society is a transformation of social practices, interpersonal relations, identity patterns, public perceptions, as well as social structures and systems by the extensive penetration of biomedical knowledges and their subsequent dissemination by the mass media.⁸ In other words, biomedicine is becoming a moral and political issue of massive normative regulation. Following the tradition of neoliberal discourse, one may observe that the social system of biomedicine produces self-regulating citizens who are more than willing to police themselves to fit the preconceived criteria of health, fitness, and well-being.⁹ Self-regulatory practices are fostered and reinforced by a moral ideal of the responsible citizen who treats health and well-being in terms of a normative obligation: “[...] health is no longer so much a gift of God but rather the task and duty of the responsible citizen. S/he has to safeguard, control and care for it, or else s/he must accept the consequences.”¹⁰

Neoliberal normative regulation promotes the formation of subject positions based on biological and biomedical criteria. In this way, knowledge and technology interfere into the very fabric of social life, fostering new forms of (bio)identity and (bio)sociality. This socially productive character of biomedical technologies and discourses is especially underscored by the theory of biomedicalization which lays specific stress on the use of bioscience to construct techno-scientific identities.¹¹ Biomedicine and biotechnology have seeped into social practices concerned with the individual’s sense of embodiment, reconstructing fundamental assumptions upon which our perception of corporality is built. The body, consequently, is

7. Robert Muchembled, *Popular Culture and Elite Culture in France, 1400–1750* (Baton Rouge: Louisiana State University Press, 1985), 31.

8. Adele E. Clarke, Janet K. Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman, *Biomedicalization. Technoscience, Health, and Illness in the U.S.* (Durham and London: Duke University Press, 2010).

9. Zygmunt Bauman, *Liquid Modernity* (Cambridge: Polity Press, 2000).

10. Elisabeth Beck-Gernsheim, “Health and Responsibility: From Social Change to Technological Change and Vice Versa,” in *The Risk Society and Beyond. Critical Issues for Social Theory*, ed. Barbara Adam (London, Thousand Oaks and New Delhi: Sage Publications, 2005), 124.

11. Clarke, Shim, Shostak, and Nelson, “Biomedicalising Genetic Health, Diseases and Identities.”

rendered a legitimate meaning by means of abstract systems of knowledge, such as genetics and genomics:

Within the broader epistemic shift from the clinical to the molecular gaze, then, medicalization and biomedicalization can be understood as the sociocultural infrastructures through which genetics, genomics, biotechnology and biomedicine emerge and on which they are built. Thus they are foundational to – set the conditions of possibility for – the development and applications of genetics and genomics.¹²

This emblematic shift towards genetics and genomics shows that biomedicalization is not only concerned with the management of observed medical conditions, but also with the appropriation of the patient's future. With the rapid development of genetic counseling, the individual's body is viewed to be structured not only by the observable distribution of phenotypic traits, but also by the anticipated impact of hidden, genotypic risk factors (including individual susceptibility for certain diseases). In other words, biomedicalization transgresses both time and space in a way that it redefines the conditions of patienthood in terms of probabilistic risk assessments.

The Birth of the Post-Patient

Let us start with a bold statement: the post-patient is neither ill nor healthy. One's present medical condition is not a dominant characteristic of post-patienthood. The post-patient lives in uncertainty, occupying a nebular space at the intersection of medical diagnosis, risk-reduction practices, and society's preconceptions concerning one's health and wellbeing.

The post-patient is born in the probabilistic discourse of genetics and genomics, in the opaque narrative of heritable vulnerabilities. It is the twofold character (i.e., genetic and environmental) of multifactorial medical conditions that condemns post-patients to dwelling in uncertainty, living a convict's life whose only intention is to roll the dice one more time in a frantic effort to cancel one's future written in the genome. Therefore, the post-patient's identity is rooted in genetic risk factors; that is, imperceptible elements of abnormal biological information that have no tangible manifestation at the moment of physical diagnosis:

Genes are reconstructed as individual risk factors, where the presence of a particular variation is seen as increasing the risk of developing a common disease: *carriers do not*

12. Clarke, Shim, Shostak, and Nelson, "Biomedicalising Genetic Health," 23.

necessarily develop the condition but have a greater chance of doing so. One great hope of contemporary research is the identification of genetic risk factors associated with a wide range of diseases.¹³

The condition of patienthood entails self-embodiment in a literal meaning of the term: the patient is fully aware of their medical condition, experiences it as unnerving abnormalities in the organism's functioning, and is able to observe the process of treatment together with its dramatic ups and downs. The patient is also in a position to recognize the authority of the "clinical gaze"; namely, the reification of the individual's corporeality by medical procedures.¹⁴ In the era of genetics and genomics, post-patienthood involves disembodiment in which the individual's medical condition is analyzed at the level of the genotype, leaving the observable body aside. Symbolically, the body becomes displaced and dismembered across a number of possible embodiments of the future. The quality of genetic risk defines post-patienthood as a construct that relates the actuality of present medical condition and the possibility of developing a serious disease in the foreseeable future. For instance, individuals diagnosed with an abnormal mutation of BRCA1 and BRCA2 genes are not suffering from breast cancer at the very moment of diagnosis. This formative moment, however, medicalizes their biography and throws it into the reality of medical procedures and conflicting lifestyle choices undertaken in the frantic effort to minimize the likelihood of developing a serious medical condition in the future.

The medicalization of biography gestures towards the agency of post-patienthood. Genetic vulnerabilities are manageable risk factors, and the actual progression of the disease in the future is determined by the individual's current activities.¹⁵ Given the life-long imperative of risk reduction, self-awareness is central to our idea of post-patienthood. The post-patient is stuck in the treadmill of compulsive self-observation, searching for symptoms of a dormant disease. In the biomedicalized reality of digital technologies, self-awareness is best epitomized by practices of self-tracking; that is, a routine of artificially intelligent self-diagnosis undertaken by individuals at risk.¹⁶ Wearable devices (e.g., smartphones, smartwatches, or smartbands with health and fitness applications) turn medical diagnosis into an

13. Paul A. Martin and Robert Dingwall, "Medical Sociology and Genetics," in *The New Blackwell Companion to Medical Sociology*, ed. William C. Cockerham (London: Blackwell Publishers, 2007), 518. Emphasis added.

14. Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (New York and London: Routledge, 2003), xix.

15. Martin, Dingwall, "Medical Sociology and Genetics."

16. Deborah Lupton, *The Quantified Self. A Sociology of Self-Tracking* (Cambridge: Polity Press, 2017).

individual practice which is no longer confined to the environment of the hospital. In this essentially digitalized environment, the post-patient is a “quantified self,” a person who uses statistical variables to express their wellbeing as a continuous flow of biomedical data.¹⁷

The post-patient’s self-tracking activities are geared towards risk reduction by means of anticipating contingent future outcomes. By focusing our attention on future contingencies, risk eludes the traditional dichotomy of truth and falsehood. It moves all our truth-claims to probabilistic future spaces in which possible consequences are labelled with distinct probabilities. Needless to say, the agency of post-patienthood resides in one’s efforts to intervene into the future distribution of counterfactuals by means of personal risk assessment and management.

Facing Risks. The Body as a Temporal Construct

When constituted within future-oriented discourses, the post-patient’s body becomes a temporal construct. We are accustomed to see the body as a living organism (biomedicine) and a site of cultural inscription (cultural studies).¹⁸ Both images, nevertheless, convey a spatial understanding of corporality. The notion of post-patienthood involves seeing the body in overtly temporal terms as a continuity of past, present, and future embodiments. We carry a burden of our medical biographies and, at the same time, are anxious to know our physical condition in the near and distant future. Time is essential to our perception of bodily functioning in terms of health amelioration or deterioration. This is especially evident in the case of post-patients whose existence is entangled within an anxious anticipation of future embodiments.

This embodied form of temporality is best rendered by the narrative of risk, which could be understood in terms of medium that facilitates binding one’s past experiences, actuality of the present day, as well as future uncertainties within the shared interpretative horizon. Since, “risks concepts are based upon the distinction between reality and possibility,”¹⁹ the notion is vital for pro-active coping strategies in which the future becomes dissolved into a multitude of future scenarios:

An array of risk studies has utilized biomedicalization theory. One emphasis has been biomedicalization as treatment for risk, such as Fosket’s research on chemoprevention as

17. Sarah Pink and Vaike Fors, “Self-tracking and Mobile Media: New Digital Materialities,” *Mobile Media and Communication*, vol. 5, no. 3 (2017): 219–238.

18. Deborah Lupton, *Medicine as Culture. Illness, Disease and the Body in Western Societies* (London: Sage Publications, 2003).

19. Furedi, *The Culture of Fear*, 25.

treatment for breast cancer risk via an assessment tool available on the Internet. Fosket asserts that breast cancer risk is now biomedicalized as a disease *per se*. Preda argues that lifestyle as risk has been biomedicalized, especially vis-à-vis HIV/AIDS, portraying how quantification is very much a part of biomedicalization.²⁰

Risk-related rationalities permeate biomedical and biotechnological settings to produce individual subject positions representing patients ‘at risk’ who are expected to police themselves in order to fit pre-defined standards of wellbeing and health. Multifactorial genetic diseases (e.g., cancer, autoimmune diseases) are especially conducive for the formation of risk-related subject positions because their management is scheduled for long-term effects, which implies behavioural change as well as the supervision of distant, future contingencies already at the onset of the disease.

It is symptomatic for sociological theories to postulate that risk-related subject positions are seen as being able to override other individual subject positions, especially those formed on a basis of class position, gender, nationality, or cultural capital.²¹ This is especially conducive of genetically inherited diseases whose incidence, statistically speaking, dissolves the structure of economic and socio-cultural distinctions. For instance, the statistics for cancer incidence in the UK indicate only that 38 percent of all cancer cases depend on the patient’s economic status and lifestyle, and as many as half of the British population born after 1960 will be diagnosed with some type of cancer.²² It is little wonder, then, that subject positions related to inherited health risks are dominating other types of social distinctions, mobilizing individuals for perpetual vigilance. Yet, the dominance of risk-related subject positions could be also observed in cases of multifactorial (i.e., preventable) diseases. Despite their genetic foundation, certain types of lung cancer, for example, could be prevented by giving up smoking. But what about second-hand smoke, automotive pollution, suspended particulate matter, or chemical additives in food? Preventability is not a zero-sum game, but rather it denotes a routine activity of risk reduction in which pro-health choices are only steps taken in a right direction. Moreover, the said risk factors refer

20. Adele E. Clarke and Janet Shim, “Medicalization and Biomedicalization Revisited: Technoscience and Transformations of Health, Illness and American Medicine,” in *Handbook of the Sociology of Health, Illness, and Healing*, ed. Bernice A. Pescosolido (New York, Dordrecht, Heidelberg, London: Springer, 2011), 188.

21. Ulrich Beck, *Risk Society. Towards a New Modernity* (London: Sage Publications, 1992); Ulrich Beck, *World Risk Society* (Cambridge: Polity Press, 1999); Ulrich Beck, *The Metamorphosis of the World* (Cambridge: Polity Press, 2016).

22. Cancer Research UK. <https://www.cancerresearchuk.org/health-professional/cancer-statistics/risk> (29.03.2022).

explicitly to lung cancer which is merely a single option extracted from myriads of other preventable medical conditions in oncology. Is it within a scope of the individual's reflexivity to deal with all risk factors simultaneously? What about non-preventable types of cancer? What about other medical conditions? Such dilemmas indicate that the reflexive management of medical conditions requires life-long risk selection and risk prioritization, which are attainable in the context of self-vigilance.

Between Risk Reflexivity and Patient Empowerment

The probabilistic nature of risk narratives puts a specific emphasis on the post-patient's agency and its decisive role in coping with health-related contingencies. When understood as a continuum of past, present, and future embodiments, the temporality of the body is an empowering quality. It encourages us to treat the body as a project *in statu nascendi*, a work-in-progress that needs to be managed and perfected upon. The body is no longer a material object that facilitates or restrain our activities. It is rather a reflexive body-self; namely, a self-made construct subsumed within the flow of autobiographical narration by means of strategic, future-oriented actions undertaken against facilitating (or constraining) character of healthcare systems and related cultural repertoire of norms, values, discourses or ideologies.

This facilitating character of healthcare systems is best rendered by the doctrine of "patient empowerment" which is understood, following the WHO guidelines, in terms of "a process through which people gain greater control over decisions and actions affecting their health."²³ The positivist ideal of scientific biomedicine in which the patient is merely a "sick body" seems to have given way to a more holistic conceptualization addressing patients as active agents who deploy their knowledge and skills in their pursuit of health and wellbeing. Likewise, medical professionals are in a position to encourage patient participation; for instance, by recognizing socio-cultural diversity of affected communities, or acknowledging the patient's experiences of disease and treatment. In this sense, the goal of empowerment is to increase the individual's capacity to become an active self-constructing agent who feels encouraged to fully understand their role in the management process, and acquire sufficient knowledge and skills to assist healthcare providers.²⁴

23. World Health Organization, *Health Promotion Glossary* (Geneva: 1998). Available at <https://www.ncbi.nlm.nih.gov/books/NBK144022/> (29.03.2022).

24. Rocco Palumbo, *The Bright Side and the Dark Side of Patient Empowerment. Co-creation and Co-destruction of Value in the Healthcare Environment* (London and New York: Springer, 2017).

Understandably, the idea of empowerment is at heart of post-patienthood. The post-patient is supposed to face the uncertain future by managing actual and possible risk factors. Since every form of social activity entails its own risk portfolio, individual actions are focused upon the selection and prioritization of health uncertainties, which paves the way for knowledgeable monitoring of risk factors. The patient is in a position to take myriads of decisions, from day-to-day dietary choices up to surgery reducing risk of breast cancer (as in the case of BRCA risk), that contribute to a network of probabilistic calculations, thusly intervening into the original volume of risk.

The post-patient's reflexivity is, however, rooted in a number of structural and cultural factors, which determine a pool of resources applied in the reflexive management of health risks:

Health lifestyles are defined here as collective patterns of health-related behavior based on choices from options available to people according to their life chances (Cockerham 2000a). This definition incorporates the dialectical relationship between life choices and life chances proposed by Weber in his lifestyle concept [...]. Whereas health and other lifestyle choices are voluntary, life chances – which primarily represent class position – either empower or constrain choices as choices and chances work off each other to determine behavioral outcomes.²⁵

The individual is expected – as in the case of cancer patients – to experience the present moment as merely an orientation towards a more or less manageable future. However, individual agency, including the reflexive management of medical conditions, is stratified, which means that one's access to resources facilitating self-knowledgeability (e.g., information, economic capital) is unevenly distributed.²⁶

Conclusions

The concept of post-patienthood teaches us that discourses of genetics and genomics are not only concerned with biology and biomedicine. When approached from the perspectives of sociology and cultural studies, searching for hereditary and environmental underpinnings of human subjectivity is a sign of

25. William C. Cockerham, "Health Lifestyle Theory and the Convergence of Agency and Structure," *Journal of Health and Social Behavior*, vol. 46, no. 1 (March 2005), 55.

26. Nicolai Bodemer and Wolfgang Gaissmaier, "Risk Communication and Health," in *Handbook of Risk Theory. Epistemology, Decision Theory Ethics, and Social Implications of Risk*, ed. Sabine Roeser, Rafaela Hillerbrand, Per Sandin, and Martin Peterson (London and New York: Springer, 2012).

a departure from what is known as the Cartesian subject. Rather than being an ideal exemplification of unity and coherence, the constitution of human subjectivity becomes an obscure combination of heredity (i.e., genetic predispositions) and environmental determinants.²⁷ Thusly understood, the subject dwells in the world of chances and risks, potentialities and vulnerabilities that remain latent as long as specific environmental conditions occur. Perceived as specific type of individual identity, post-patienthood is a perfect illustration of the aforementioned postulates. The post-patient's body is a temporal construct, a continuum of actual and possible embodiments that leaves the individual in uncertainty as to the future. It is little wonder that risk-related discourses assume a central role in the constitution of human subjectivity as the "probabilistic self"; that is, a nebular construct which exists discursively as an element of elaborate probabilistic assessments. The post-patient is subjected to a process of de-centralisation in which the *soma* is no longer viewed as an autonomous entity, self-explicable by the virtues of its cohesiveness and completeness, and becomes a network of dispersed, future-oriented subject positions each constituted and rendered explicable by probabilistic assessments of health risks.

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