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Beyond race: social inequalities. A critique of race-based medicine

TERESA ANDREANI









Beyond race: social inequalities. A critique of race-based medicine

Teresa Andreani*

ABSTRACT: The term race has been used until the half of the XX century with the ideological pretext of dividing humans on a scientific base. Although today biological racism is obsolete and the social nature of races is acknowledged, advances in genetics and genomics have given the ground to a revival of race as a biological concept. This holds true particularly in the field of medicine, where an increasing trend is to adopt race-specific strategies for treatments. Race-based medicine is further developing and raises many concerns. The aim of this paper is to investigate its limits from the scientific and social perspective and to overturn its paradigm by analysing the impact of social factors and inequalities on individual health.

KEYWORDS: race; drugs; minorities' health disparities; social inequalities; United States of America

Summary: 1. Introduction - 2. What race-based medicine is? - 3. Race as a social construction: the interplay between history, science and society - 4. The revival of race as a biological concept - 5. The BiDil case: genes, drugs and health disparities - 6. The impact of social inequalities on individual health 7. Disparities in mortality by Covid-19, the role of law and bioethics: a conclusive overview

1. Introduction

Since the last decade, precision medicine is widely considered the inspiring approach for the medicine of the future. Overcoming the traditional approach "one-fits-all", its aim is to take into account the multidimensional nature of individual health and to reach individualised diagnosis and therapy¹.

In occasion of the launch of Precision Medicine Initiative, President Barack Obama stated: «that's the promise of precision medicine: to deliver the right treatments, at the right time, every time to the right person»². He emphasised the biological uniqueness of each individual and enthusiastically affirmed that precision medicine was finally able to recognise it³. Further, his ascendance as the first black President of the United States of America was perceived as the beginning of a post-racial era for the country that, after being dramatically marked by racial discriminations and conflicts, could finally reach "colour-blindness"⁴. To the contrary, the years and events following his election have dramatically disregarded this expectation, revealing that the fate of racial conflicts in America was a societal and collective question and could not depend on a single man⁵. One for all, the latest protests exploded after the dramatic murder of George Floyd

^{*} Student at the University of Trento, Faculty of Law.

¹ A definition by U.S. Library of Medicine, available online at https://ghr.nlm.nih.gov/primer/precisionmedicine/definition

² The White House, Office of the Press Secretary. Remarks by the President on Precision Medicine: President Barack Obama, January 30, 2015, available online at https://obamawhitehouse.archives.gov/the-press-office/2015/01/30/remarks-president-precision-medicine

³ V.R. Newkirk, *Precision Medicine's Post-racial Promise, The Atlantic,* June 8, 2016.

⁴ National Public Radio, A New, "Post-Racial Political Era in America", January 28, 2008.

⁵ "Is America ready for a man like my husband?" Michelle Obama asked herself in the election day while remembering they were descendants of slave. A memory she reported in her personal documentary *Becoming*.

have proven that the "question of race" is actual, urgent and intersects every aspect of the American society. In particular, the concept of race has resumed a role in medicine where the "race-based" medical approach has flourished.

2. What is race-based medicine?

The scientific progress in the fields of genetics⁶ and genomics⁷ has been strongly promoted and, in the last two decades, has led to significant developments. The latter ones have played a crucial role in the medical field where they have laid the foundations of race-based medicine.

Race-based medicine can be defined as a medical approach that bases diagnosis and therapy on the genetic common factors among populations or ethnicities⁸. Structurally, it relies on the paradigmatic assumption of the existence of a link between the presence of genes, shared by specific groups, and the predisposition to certain diseases and the response to certain drugs.

Nowadays, studies on the genetic predisposition to diseases have been conducted worldwide⁹. Some interpretations of scientific data pretend to demonstrate that some types of tumours, diabetes and cardiovascular diseases are more likely to affect one population rather than the others. In particular, the researchers focus their attention on the role of ethnic differences in the predisposition to cardiovascular risks and in the response to drugs for hearth failure¹⁰. By way of example, a 1999 study on differences in left ventricular dysfunction among human populations concluded that black patients affected by heart failure have an higher mortality rate than white patients affected by the same pathology, validating the race-based approach¹¹.

In spite of the remarkable division among researchers on the point, the race-based approach is applied in clinics and leads to race-based diagnosis and therapy¹². Further, it influenced the study of drug responses

⁶ Stemmed by the discoveries of Gregor Mendel in the 19th century, genetics is the study of laws governing functioning of genes in hereditary transmission, *Encyclopedia Britannica*.

⁷ Flourished during the Eighties, genomics is the study of the structure, function and inheritance of the entire set of genetic materials which is named genome, *Encyclopedia Britannica*.

⁸ In this paper uses the term "population" or "ethnicity" to describe human groups considering their geographical origins or their social identities. The paper reproduces the terms "black" and "white" when they are used in scientific studies.

⁹ WORLD HEALTH ORGANIZATION, *Human Genomics in Global health: Genes and human diseases*, available online at https://www.who.int/genomics/en/.

¹⁰ J. S.W Taylor, G.R. Hellis, Racial Differences in Responses to Drug Treatment: Implications for Pharmacotherapy of Hearth Failure, in American Journal of Cardiovascular Drugs, 2002.

¹¹ D.L DRIES, D.V. EXNER, B.J. GERSH, H. A. COOPER, P.E. CARSON, M.J. DOMANSKI, *Racial differences in the outcome of left ventricular disfunction*, in *The New England Journal of Medicine*, 1999.

¹² S. SATEL, *I am racial profiling doctor*, in *NY Times*, 2002. In opposition to this view: R.S. COOPER, J.S. KAUFMAN, R. WARD, *Race and Genomics*, in *The New England Journal of Medicine*, 2003; R.S. SCHWARTZ, *Racial Profiling in Medical Research*, in *The New England Journal of Medicine*, 2001.

and has led the growth of pharmacogenomics¹³, an upward field which has a crucial impact on the pharmaceutical market. As will be further stressed in detail, BidDil, a drug to cure hearth failure, was the first drug ever to be labelled for "self-identified black patients" and approved with race-specific target by the U.S. Food and Drug Administration¹⁴.

The latter event has strongly increased the attention on race-based medicine and a discussion has raged among experts of the scientific, social and legal field¹⁵. Thereby, criticism on its assumptions and implications have been expressed on multiple levels. First of all, in the wake of genetics and genomic, race-based medicine potentially reinforces "race" as a biological concept. Thus, the biological inexistence of race and its social nature needs to be urgently examined. Secondly, this approach has given the floor to the development of race-specific drugs which, in lack of scientific base, appears to be guided by corporations' aim to profit. Lastly, reconducting the existing health disparities to genetic differences among populations, race-based medicine appears to ignore the role of social determinants on health and to naturalise the existing social inequalities among populations.

The above issues will be analysed in the following sections in the context of a general critique of race-based medicine.

3. Race as a social construction: the interplay between history, science and society

Race-based medicine unequivocally brings back the term "race" in the scientific and social arena¹⁶. Historically, the "question of race" is never ending and traces back to the very origin of scientific theories on human biodiversity.

For the first time in 1758 Linnaeus proposed a taxonomy of human biodiversity through the concept or "race"¹⁷. Since his proposal, the theory of race-division was perpetuated for the two following centuries in different versions by a plenty of scientists and was supported by many physical anthropologists¹⁸. Then, racial theories gave birth to racist theories and, as the course of events in the Nineteenth and Twentieth centuries demonstrate, the latter ones were able to justify and feed the political systems and powers on the ideological level¹⁹.

¹³ Pharmacogenomics is a new field that studies how genes affect the response to drugs, combining pharmacology and genomics to develop medications and doses that will be tailored to a person's genetic makeup, *National Human genome Research Institute*.

¹⁴ R. Temple, N.L. Stockbridge, BiDil for heath failure in black patients: The U.S: Food and Drug Administration perspective, in Annals of Internal Medicine, 2007.

¹⁵ For a wise summary of the intersectorial emerging issues: K.N. Maglo, J. Rubistein, B. Huang, R.F. Ittenbach, *BiDil in the Clinic: An Interdisciplinary Investigation of Physicians' Prescription Patterns of Race-based Therapy*, in *AJOB Empirical Bioethics*, 2014.

 $^{^{16}}$ M. Tomasi, *Genetica e Costituzione*, Trento, 2019, p. 161-162.

¹⁷ J. Marks, *Human Biodiversity: Genes, Race and History,* New York, 1994, p.6.

¹⁸ Ibid.

¹⁹ J. Marks, *op.cit*, pp.6-19.

The Nineteenth century's European colonialism was validated by a general belief in the inferiority of non-Europeans which could find consent in scientific community of the time²⁰. In continuity with the precedent era²¹, eugenics and racial hygiene were promoted long before Hitler came to power by numerous of prominent German scientists. Afterwards, biological racism was implemented during the Nazi era in Germany and in the Fascist Italy. Reflecting the hierarchical division of humans on every aspect of society, Nazism made a version of social Darwinism reality. The Nazi political system was directly fed and justified by the scientists of the time and was finally taken to its extreme consequences²²: the commission of unprecedent atrocities, as the practice of eugenics and the extermination of people categorised as inferior. Biological racism was then publicly embraced by the Fascist regime with the adoption of "Il Manifesto della razza", also named "manifesto of racist scientists" ²³, on which racist laws against the Jews were legitimated²⁴.

For these reasons, since the end of the destructive II World war and the fall of the totalitarian regimes in central Europe, the term "race" has indelibly assumed a tragical connotation for the Western World. At the beginning of the Fifties, the scientific community widely condemned biological racism and expressed a general consent on the biological non-existence of human races. As a signal of break, in the 1950 UNESCO Declaration on "the question of race" it can be read:

«Scientists have reached general agreement in recognising that mankind is one: that all men belong to the same species, Homo sapiens... the unity of mankind from both the biological and social viewpoints is the main thing. To recognise this and to act accordingly is the first requirement of modern man»²⁵.

From that moment on, the term started to be used with a descriptive value in reference to populations or ethnicities and acquired an anti-discriminatory function, as it does in the 1948 Universal Declaration of Human Rights and many other international declarations and constitutional documents dated to the mid of

²³ "Il Manifesto della razza" was published in July 1938 and signed by ten prominent Italian scientists. It is composed of ten assertive declarations on the existence of the Italian race: "1. Human races do exist (...) 3. The concept of race is purely biological (...) 4. Nowadays, Italian population is for the majority of arian origins...a pure Italian race do exist (...) It is time for Italians to fiercely declare themselves racist!".

²⁰ G. Ruata, *Le malattie mentali della razza negra*, in «Giornale di psichiatria clinica e tecnica manicomiale», 1907. Racist theories were applied in the field of psychiatry and were particularly directed to the Africans.

²¹ K. WEIGMANN, *In the name of science, the role of biologists in Nazi atrocities: lessons for today's scientists*, in *Science & Society*, 2001. In 1905 the "Society for Racial Hygiene" was founded. In the twenties Erwin Baur, Eugen Fisher and Fritz Lenz published "Human teaching and Racial Hygiene", cornerstone of the following Nazi policies.

²² K. WEIGMANN, op.cit.

²⁴ Since September 1938 to 1942, thirty racist laws were gradually introduced to discriminate the Jews in every aspect of their life.

²⁵ UNESCO, *The Race question*, 1950.

the century²⁶. Today, even if the term has survived through the decades in numerous documents, it is often considered divisive and ambiguous²⁷. By way of example, despite the numerous requests to replace it by the scientific community²⁸, "race" is mentioned in article 3 of the Italian Constitution²⁹.

The ongoing controversy where to delate the term or not indicates that societies are still dealing with the question of race. And even after the scientific community rejected it as a biological concept, discriminations in the name of human division by races diffusely continued to be implemented. Most of all countries, the United States of America persevered to be a crude scenery of institutional racism and discriminations against African Americans. That has been dramatically demonstrated in the field of medical research, as the Tuskegee studies on syphilis has revealed. From 1932 to 1972 in Alabama research studies on syphilis were made on 600 black men without their informed consent. Without any aim to treat them, they were used as test subject for scientific research in change of free medical exams, meals and burial insurance³⁰. During the Segregation era and the numerous and recurring civil disorders, it was only with the introduction of the Civil Rights Act in 1964 and the Voting Right Act of 1965 that a step towards substantial equality was made³¹. Yet still, beyond the recognition of formal equality, racism, racial discriminations and inequalities continue to be an alarming and unsolved problem³². It has been recently said that: "race in America is a cosmology, and entire world view"³³.

During the Eighties, the scientific progress in the field of genetics and genomics began³⁴ and was able to irrevocably demonstrate the biological non-existence of human races. In particular, this knowledge was gained with the conclusion of the DNA sequencing by the Human Genome Project in 2003³⁵. The latter

²⁶ UNITED NATIONS GENERAL ASSEMBLY, The Universal Declaration of Human Rights, 1947: "Art.2: Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion ...". In continuity with this perspective: UNESCO, Declaration in Race and Racial prejudice, 1978.

²⁷ On July 2018, France has deleted the term "race" mentioned in the article 1 of the Constitution adopted in 1946, declaring its lack of scientific validity and its ambiguity.

²⁸ In 2014, the first proposal was made by the scientists Olga Rickards and Gianfranco Biondi who published an appeal "for the abolition of the term race". In the following year, it was joined by the Italian Institute of anthropology (ISITA), the University National Association of cultural anthropologists (ANUAC) and the Anthropological Italian Association (AAI) and supported by the Italian Jewish communities.

²⁹ For a detailed description of the conflicting positions among the legal experts on the removal of the term: M. Tomasi, *op.cit.*, pp.157-159.

³⁰ CENTRE FOR DISEASES CONTROL AND PREVENTION, *Timeline of "The Tuskegee Study of Untreated Syphilis in the Negro Male"*, available online at https://www.cdc.gov/tuskegee/timeline.htm.

³¹ The Civil Rights Act was approved by the American Congress in 1964 with the aim to end discrimination of African Americans. It was followed by the Voting Right Act of 1956 which recognised them effectiveness of the right to vote. For an exhaustive chronology of events concerning racial discrimination in America: LIBRARY OF THE CONGRESS, Legal timeline: *The Civil Rights Act of 1964: A Long Struggle for Freedom*, online at https://www.loc.gov/exhibits/civil-rights-act/legal-events-timeline.html.

³² PEW RESEARCH CENTER, *On Views of Race and Inequality, Blacks and Whites are Worlds Apart*, 2016, online at https://www.pewsocialtrends.org/2016/06/27/on-views-of-race-and-inequality-blacks-and-whites-are-worlds-apart/.

³³ E.M HAMMONDS, Straw Men and Their Followers: the return of biological race, in Is Race "Real"?, 2006.

NATIONAL HUMAN GENOME INSTITUTE, Genetic Timeline, available online at https://www.genome.gov/Pages/Education/GeneticTimeline.pdf.

³⁵ The Human Genome Project (1990-2003) was an international project, coordinated by the National Human Genome Institute and the U.S. Department of Energy, whose primary goal was to discover the complete set of human genes and to determine the complete sequence of DNA bases in the human genome, *Human Genome Information Archive*.

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achievement has spread and strengthened the theory of the biological uniqueness of the individual. As the World Health Organisation reported:

«Studies of genome diversity indicate that each of us is unique. The genetic differences that exist between two individuals of different racial backgrounds are not greater than those between two individuals of the same race... the more that is learnt about the individual uniqueness and diversity of human beings, the less the concept of "race" seem to have any meaning".

The existing differences among humans do not imply the biological concept of race. The term "race" is biologically meaningless: each human-being is an autonomous biological entity³⁷.

So far, the conducted historical overview on the question of race gives the ground to an observation and a conclusive deduction. First, historical experiences of biological racism have showed that the interplay between history, science and society is complex and mutual. The words of J. Marks intensely express this complexity:

«In humans, the biological differences among human groups reinforce the social divisions that may also exist. If all social groups received equal treatment – had equal rights and equal opportunities for advancement – the study of the biological differences among them would be straightforward. It is not straightforward, however, since the differential treatment often accorded to different groups can find a validation in the biological differences that may accompany them»³⁸.

The study of biological human diversity appears not to be value-neutral. So, science is definitely able to justify the contemporary political system, to maintain social hierarchies and to deepen social disparities. Consequently, a burden of responsibility is placed on scientists, who have to monitor the social implications of the theories they support³⁹.

Finally, the recent scientific advances are able to unequivocally demonstrate what history has suggested: races and racism are products of historical and political events⁴⁰. In a word, race is merely a social construction⁴¹.

³⁹ J. Marks, *op.cit.*, p.102.

³⁶ World Health Organization, Report Genomics and World Health, 2002, p.70.

³⁷ J. Marks, *Human Biodiversity: genes, race and history*, 1995, p.102.

³⁸ Ihid

 $^{^{40}}$ N. Zack, Social Construction and Racial identities, in The Oxford Handbook of Philosophy and Race, 2017.

⁴¹ J. Marks, *op.cit*, pp.111-113.

4. The revival of race as a biological concept

Notwithstanding the above-reported scientific advances in genetic and genomics, the biological conception of race has been counterintuitively revived. It is precisely during the Nineties that the term "race" has begun to be used again in the scientific field to identify genetic similarities and differences among populations. Since the beginning of post-genomic era, marked by the conclusion of the Human Genome Project⁴², race is experiencing a revival. This paradox has been clearly highlighted by M. Tomasi:

«Genetics lives and feeds this contradictory tension: on the one hand, it destroys the scientific validity of the concept of race; on the other hand, it increments the evocative value of it, reinforcing a race-inclined way of thinking» 43.

Since race as a biological concept is being reintroduced and revalidated in the scientific debate, potential human division on that ground have arisen again, as D. Roberts has strongly advocated:

«Instead of hammering the last nail in the coffin of an obsolete system, the science that emerged from sequencing the human genome was shaped by a resurgence of the interest in race-based genetic variation. Some scientists are claiming that clusters of genetic similarity detected with novel genomic theories [...] prove that human racial differences are real and significant.⁴⁴.

So, the resurgence of the concept of race as a biological category is tangible⁴⁵. This particularly holds true in the American medical research and clinical practice where the race-based approach, anchored in the idea that some populations are more likely to be affected by certain disease because of their innate genetic pool, has flourished⁴⁶.

5. The BiDil case: genes, drugs and health disparities

In consideration of the revival of race as a biological concept, pharmaceutical industries have started to develop and market race-targeted products⁴⁷. In this regard, the already mentioned BiDil is a leading case. A

⁴² S. Guttinger, J. Dupré, Genomics and Postgenomics, in The Stanford Encyclopedia of Philosophy, 2016.

 $^{^{43}}$ M. Toması, *op.cit.*, p.131 e 150. Translation by the author.

⁴⁴ D.E. ROBERTS, Fatal Invention: How Science, Politics and Big Business Re-create Race in the Twenty-First Century, 2011, Preface.

⁴⁵ N. ABU EL-HAJ, The Genetic Reinscription of Race, in The Annual Review of Anthropology, 2007.

⁴⁶ M.O. Fofana, The Spectrum of Race in American Medicine, in Medical Humanities, 2013.

⁴⁷ D.E. ROBERTS, *op.cit*.

meticulous analysis of this can deconstruct the validity of scientific arguments on which the drug's efficacy was pretended to be based and can disclose the commercial purposes that motivated its marketing⁴⁸.

BiDil, a drug to cure heart failure labelled for "self-identified black men", was authorised by the FDA in 2005. However, the first request for its approval had been denied by the Administration in 1997. In its original version the drug was not conceptualised as race-specific. Neither, since the first version, its ingredients were changed: it was and it still is a pill derived from the mixture of hydralazine and isosorbite dinitrate, two generic drugs previously known in the market⁴⁹. It was after the first patent's denial that NitroMed, a pharmaceutical industry from Massachusetts, acquired the drug's intellectual property from the inventor, Doctor Jay Cohn, and announced an amendment in the label. The industry applied again for a patent but specified that "the present invention provides methods for treating and preventing mortality associated with heart failure in African American patients". Accordingly, for the first time ever, the FDA approved a race-targeted drug. In doing so, it validated the idea that its efficacy was related to blacks' distinctive genetic factors. Though, the relation between the drug's efficiency and blacks' genetic factors was found out to be speculative.

The approval was based on two cornerstones supported by the mentioned 1999 study on the left ventricular disfunction⁵¹: a statistic of 2:1 disparity rate between blacks and withes in mortality related to heart failure and the impossibility to explain it by socio-economic factors. However, both the statistic and its underlying assumption can be challenged for two reasons⁵². First, by the time the study was concluded the number of available data grew and showed a substantial narrowing of the gap in heart failure mortality between blacks and whites⁵³. Second, an underestimation of the role of social factors in the predisposition to the disease was pointed out. Indeed, the 1999 founding study ignored the existence of many other researches which were able to show the strong role that social factors like diet, environment and salary play in the elevation of blood pressure and hypertension⁵⁴. Moreover, a further demonstration of the scientific inconsistency of the drug's efficacy was given some years later by NitroMed and the FDA themselves. They admitted that the labelled "self-identification" had been used by scientist as a surrogate for genetic markers⁵⁵. If, without any doubt,

⁴⁸ D.E. Roberts, What's wrong with race-based medicine?, in Minnesota Journal of Law, Science & Technology, 2011, p.2.

⁴⁹ J. Khan, How a Drug Becomes "Ethnic", in Yale Journal of Health Policy, Law and Ethics, 2004, p.19.

⁵⁰ U.S. Patent No. 6,465,463, available online at <a href="http://patft.uspto.gov/netacgi/nph-Parser?Sect1=PTO1&Sect2=HITOFF&d=PALL&p=1&u=%2Fnetahtml%2FPTO%2Fsrchnum.htm&r=1&f=G&l=50&s1=6,465,463.PN.&O S=PN/6,465,463&RS=PN/6,465,463.

⁵¹ D.L Dries, D.V. Exner, B.J. Gersh, H. A. Cooper, P.E. Carson, M.J. Domanski, *op.cit*.

⁵² J. KHAN, *op.cit.*, p.19.

⁵³ *Ibid.*, p.20.

⁵⁴ W.W. Dressler, Lifestyle, Stress and Blood Pressure in a Southern Black Community, in Psychosomatic Medicine, 1990. M.J. Klag, PK Whelton, J. Coresh, L.H. Kuller, The Association of Skin Color with Blood Pressure in US Blacks with Low Socioeconomic Status, in JAMA Network, 1991. D.R. Williams, Black-Whites Differences in Blooding Pressure: The Role of Social Factors, in Ethnicity & Diseases, 1992.

⁵⁵ J. Khan, op.cit., p.26-28 and D.E. Roberts, op.cit. p.5.

the drug was efficient in prolonging patients' life expectation, anyway its efficiency could not be related to black's specific genetic factors⁵⁶.

In the light of this reconstruction, the real reasons basing the drug's marketing are disclosed. Targeting BiDil as the first race-specific drug ever, NitroMed asked for a "prior art" invention's patent and gained a 15 years-long patent while, with the original version of the drug, it would have only gained a 7 years-long one⁵⁷. As D. Roberts has concisely stated:

«NitroMed did not make money from a drug that was developed to treat heart failure in black patients. It made money by converting a drug for heart failure into a drug for African Americans base on the unscientific claim about racial differences.»⁵⁸.

Example of strategic exploitation of the revival of race in medicine, the case in question appears to be a dowel of a general and increasing trend of capitalisation of race-specific drugs⁵⁹. Comprehensively, the analysis of the BiDil case gives the ground to two general considerations.

First, the resurgence of race as a biological category is strongly guided by the commercial interests. Many corporations are allowed to develop race-specific products with the only aim to gain regulatory and commercial advantages⁶⁰. This is a perilous tendency that must be refrained and controlled, as Silvio Garattini has concisely warned, stating: «the pharmaceutical market must not be allowed to take over knowledge»⁶¹. It is a renowned fact that the scientific and medical research are endangered by profit-making objectives. Their independency, essential premise to the scientific, needs to be protected by a conscious regulatory system that is able to discourage the pharmaceutical industries, whose role is indispensable in the progress of the scientific research, in their speculative aim⁶². A conscious regulatory system could also guarantee that medical research is permeated by integrity and ethics and guided by the aim to advance in the field of human care in order to deliver better standards of health⁶³.

Secondly, even if, at first sight, the race-based medicine appears to be crucially corroborated by pharmacogenetics, a distinction has to occur. On the one hand, pharmacogenomics is a scientifically founded field and can be seen as a promising attempt in the individualization of care promoted by precision medicine.

⁵⁶ R. Temple, N.L. Stockbridge, op.cit.

⁵⁷ KHAN, *op.cit.*, p.32.

⁵⁸ D.E. ROBERTS, *op.cit.*, p.20.

⁵⁹ KHAN, Beyond BiDil: the expanding embrace of race in biomedical research and product development, in St Louis University Journal of Health Law & Policy, 2009.

⁶⁰ KHAN, Exploiting Race in Drug Development: BiDil's Interim Model of Pharmacogenomics, in Social Studies of Science, 2008.

⁶¹ This warning was made by Silvio Garattini, a prominent Italian scientist, during the event "Emergenza Covid-19: quali sfide per la ricerca?" held on the 8th of April 2020. Translation by the author.

⁶² For a detailed analysis of pharmaceutical industries' role in the increase of the gap between needs of public health and medical research: S. GARATTINI, The risk of bias from omitted research: evidences must be independently sought and free of economic interests, in The BMJ, 2000.

⁶³ S. GARATTINI, L'Agenzia del Farmaco Europea è tuttora troppo legata all'industria, in Politiche del farmaco, 2020.

However, the knowledge emerging by discoveries in the field is not absolute and needs to be structurally integrated with the role of the social determinants played on health. Oppositely, emphasizing and absolutizing the link between genetic factors and certain diseases, the race-based approach is reductive and ineffective in understanding the multidimensional nature of individual health. The approach in question blindly ignores the crucial impact of the social determinants on health and ends up attributing the persistent health disparities among ethnicities to innate genetic differences, naturalising and embodying them⁶⁴.

6. The impact of social inequalities on individual health

In order to show that race-based medicine's assumption on the genetic determinism in predisposition to diseases is misleading, it is necessary to introduce the relevance of the social determinants of health by choosing one particular social context as case study. As always, the American case is particularly demonstrative on the point. In the United States on America numerous surveys have reported health disparities among African Americans and white Americans. It has been found out that the average life expectancy of black Americans is 5.5 years less than whites and their mortality for hearth diseases and cancer is 1.3 times higher, 2 times higher for diabetes and more than 8.6 times higher for AIDS⁶⁵. Considering maternal and infant health, African Americans mothers are 2.3 times more likely to receive late or no prenatal care, the infant mortality rate is 2.3 times higher and black infants are 3.8 times more likely to die from complications related to low birthweight⁶⁶. Furthermore, a permanent plague for the black Americans' health status is violence⁶⁷: they experience a 6 times higher mortality rate for different types of violence, like domestic violence⁶⁸ and police brutality⁶⁹. For instance, although they account for 13% of the U.S. population, more than a quarter of people killed by the police in 2020 were blacks⁷⁰.

The reported outstanding health disparities can be explained by social factors⁷¹. In particular, two social determinants of health should be accounted: a general one and a specific one.

The first general factor is the socioeconomic deprivation which is affecting African Americans. According to Pew Research Center, the last U.S. survey made in 2014 reported that 26% of blacks people live in poverty in

70 Ibid.

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⁶⁴ C.C. Gravlee, *How Race Become Biology, Embodiment of Social Inequality*, in *American Journal of Physical Anthropology*, 2009. On the same line: E.M Hammonds, *op.cit.* and D.E. Roberts, *op.cit.* p.16.

⁶⁵ N. KRIEGER, If "race" is the answer, what is the question? – on "race", racism and health: a social epidemiologist's perspective, in Is Race "Real"?, 2006. Table 1.

⁶⁶ U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES OFFICE OF MINORITY HEALTH, *Infant Mortality and African Americans*, available at https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=23.

⁶⁷ D. Schneider, M.R. Greenberg, D. Choi, Violence as a public health priority for black Americans, in Journal of National Medical Association, 1992.

⁶⁸ B.S. CENTERWALL, *Race, socioeconomic status, and domestic violence, Atlanta, 1971-1972,* in *American Journal of Public health, 1984*. ⁶⁹ S.A. Schwartz, *Police Brutality and racism in America,* in *ScienceDirect, 2020*.

⁷¹ N. KRIEGER, op.cit.

comparison with 10% of white people⁷². Looking at health data, an increment of 1,8 to 4,3 times in the rate of premature mortality between people living below the poverty line and people living below it is reported⁷³. Poverty appears to be «the most influential social determinant of mortality»⁷⁴. Actually, the individual socioeconomic status is deeply decisive in health and predisposition to diseases: «people with the lowest income and who were less educated... are less healthy than the wealthiest and the most educated» a study on U.S. socioeconomic disparities in health has further concluded⁷⁵.

Secondly, in the recent years many studies have raised the attention on a specific factor which, among many others, determines health conditions: the personal experiences of racial discrimination and racism that African Americans, like other ethnic minorities, frequently live. In particular, the study "Experience of Discrimination" involved people from different ethnicities and asked them to report personal experiences of racial discriminations⁷⁶. These events were found out to generate psychological stress, worsening of people's self-esteem and increasing the consume of cigarettes: all factors connected to cardiovascular risks⁷⁷. To date, the significant role of indirect effects of the experience of discrimination on the predisposition to cardiovascular risks is widely documented⁷⁸.

As briefly reported with significant examples of the American social context, the role of the social factors in the determination of health is decisive. On this point, the scientists' responsibility towards society resurfaces, as N. Krieger highlighted:

«A scientifically responsible position on addressing racial/ethnic disparities in health would entail frank recognition of the social reality of popular and scientific racism and the harms they wreak on human health»⁷⁹.

This knowledge should guide scientific and medical researchers in their efforts to enlarge the horizon of care: that the existing health disparities must be mainly explained by social inequalities.

7. Disparities in mortality by Covid-19, the role of law and bioethics: a conclusive overview

⁷² Pew Research Center, *op.cit*.

⁷³ N. Krieger, *op.cit.*, Table 2.

⁷⁴ Silvio Garattini shared this statement in the event "Emergenza Covid-19: quali sfide per la ricerca?" held on the 8th of April 2020.

⁷⁵ P. A. Braveman, C. Cubbin, S. Egerter, D. R. Williams, *Socioeconomic Disparities in Health in the United States: What the Patterns Tell Us*, in *American Journal of Public Health*, 2010.

⁷⁶ N. KRIEGER, K. SMITH, D. NAISHADHAM, C. HARTMAN, E. M. BARBEAU, *Experiences of discrimination: validity and reliability of a self-report measures for population health research on racism and health*, in *Social Science & Medicine*, 2005.

⁷⁷ *Ibid*.

⁷⁸ D. R. WILLIAMS, H. NEIGHBORS, *Racism, discrimination and hypertension: evidence and needed research, Ethnicities & Diseases*, 2001.
⁷⁹ N. KRIEGER, *If "race" is the answer, what is the question? – on "race", racism and health: a social epidemiologist's perspective*, in *Is Race "Real"?*, 2006.

An ulterior demonstration of the fact that health disparities trace back to the dramatic social inequalities afflicting certain populations has been given by the outbreak of the contemporary pandemic.

Although covid-19 has been initially called "the great equaliser"80, the collected data on infection and the mortality rates show that the novel coronavirus is killing African Americans more than any other population in the United States⁸¹. In particular, the disproportionality in mortality rate between them and the other population is outstanding. Averagely, the difference ranges from 10 to 35 %82, with particular intensity in the South of the country: in Louisiana, blacks are 33% of the state population but they are the 70% of deaths and in Alabama, while representing 26 % of the state population, they are 44 % of the deaths⁸³. Once again, their higher rate to be infected and to die has to be attributed to the social conditions black people live: they do jobs that expose them to close contact with other people, they travel more with public transportation and they are poorer and unable to have proper access to healthcare⁸⁴. Further, for the same reported socioeconomic reasons, they are often affected by previous medical conditions, like cardiovascular and respiratory diseases, in case of which the virus is lethal.

The latter remarks give the opportunity to recall some insights that have been suggested along the precedent pages. In relation to the interplay between history, science and society, the scientists' burden of responsibility towards society is a concept that has diffusely surfaced. As historically demonstrated, science itself was tragically tainted by racist ideologies and was able to justify and feed discriminations. So, there is no certainty that scientific racism is irreversibly declined⁸⁵. In order not to outline new path to ancient discriminations, the scientific community and physicians should rigorously guarantee the scientific validity of the theories they support by ensuring the independency of scientific research and monitor the following social implications. On the point, the role of law is vital. Firstly, in accordance to the core of constitutionalism, law should control science as a power and should be vigilant on the mutual and fragile interaction between science and society⁸⁶. Secondly, law is a decisive tool to encourage the independency of scientific research from economic interest and its permeability to integrity and ethics⁸⁷. A need of accurate legislations that are finalised to this goal is generally recognised, with particular intensity in the research and development of

⁸⁰ The New York Times: The Daily, Why Is the Pandemic Killing So Many Black Americans?, May 20, 2020.

⁸¹ J. Bouie, Why Coronavirus is killing African-Americans More Than Others, The New York Times, April 14, 2020.

⁸² APM RESEARCH LAB, The color of coronavirus: covid-19 deaths by race and ethnicities in the U.S., May 7, 2020.

⁸³ J. BOUIE, op.cit.

⁸⁴ C. RO, Coronavirus: Why some racial groups are more vulnerable, BBC, April 21, 2020.

⁸⁵ R. Bowser, Racial Profiling in Health Care: An Institutional Analysis of Medical Treatments Disparities, in Michigan Journal of Race

⁸⁶ C. CASONATO, La scienza come parametro interposto di costituzionalità, in Associazione Italiana dei Costituzionalisti, 2016, p.4.

⁸⁷ S. Garattini, The risk of bias from omitted research: evidences must be independently sought and free of economic interests, in The BMJ, 2000.

drugs⁸⁸. Furthermore, having identified poverty as the most influential social determinant of health, the importance of social policies in order to reduce social inequalities and to guarantee free or affordable access to healthcare is extreme⁸⁹. Particularly in the American context, the advance to a gradual achievement of social justice in healthcare is stormy⁹⁰. Ultimately, it is necessary to mention the role of bioethics on the point as well. It is all the more urgent because a new branch, named "Black Bioethics", is rebelling against the traditional boundaries of the field and is claiming to explore crucial topics related to black people's health. According to this spreading paradigm, bioethics should investigate human health in its broadest sense by addressing topics like health justice, institutional racism and police brutality⁹¹. This process of separation into multiple and unconnected branches is ascribed to the inability of the field to confront with socially inclined topics, particularly the ones profoundly experienced by black people and other minorities⁹². So, in order to continue to be eminently capable of examining and interpreting society, bioethics should become «sociologically and historically informed»⁹³ and, having recognized the role of social determinants of health, should raise the attention to moral dilemmas about the most vulnerable and marginalized ethnic minorities' health crisis which originates from social inequity and injustice⁹⁴. It is the only chance for bioethics to be part of a worldwide, systemic, real and lasting social change⁹⁵.

In the light of all mentioned argumentations, a conclusive frame on race-based medicine can be depicted. The criticised approach reinforces the biological concept of race and dangerously justifies health disparities on the ground of inherent genetic differences among populations. In doing so, it ignores the multidimensional nature of individual health and obscures the importance of social determinants and inequalities on health. Finally, race-based medicine must be refused. To the contrary, if medicine went beyond the category of race and dived into social reality then an overwhelming conclusion would prevail: «a more just (and equal) society will be a healthier one»⁹⁶.

⁸⁸ C. CASONATO, I farmaci, fra speculazioni e logiche costituzionali, in Associazione Italiana dei Costituzionalisti, 2017.

⁸⁹ M. P. Behnken, Book review: Just Medicine: A Cure for Racial Inequalities in American Health Care, in Journal of Critical Thought and Praxis, 2018.

⁹⁰ J. E. DALE, K. WATERBROOK, J. S. ALPERT, Why do so Many Americans oppose the Affordable Care Act?, in The American Journal of Medicine, 2015.

⁹¹ M. DANIS, Y. WILSON, A. WHITE, Bioethicists Can and Should Contribute to Adressing Racism, in American Journal of Bioethics, 2016.

⁹² K. RAY, Black Bioethics and How the Failures of the Profession Paved the Way for Its Existence, in Bioethics.net, 2020.

⁹³ J. Hoberman, Why Bioethics Has a Race Problem, in Hastings Centre Report, 2016.

⁹⁴ Ibid.

⁹⁵ K. RAY, op.cit.

⁹⁶ D. ROBERTS, op.cit.