

BIOETHICS IN ACTION

BIOETHICS
& RACISM

PRACTICES
CONFLICTS
NEGOTIATIONS
& STRUGGLE(S)

BOOK OF ABSTRACTS

illustrated by Alice Toietta



This drawings book was inspired on the Bioethics in Action Seminar series organized by the RUEBES in Spring 2021.

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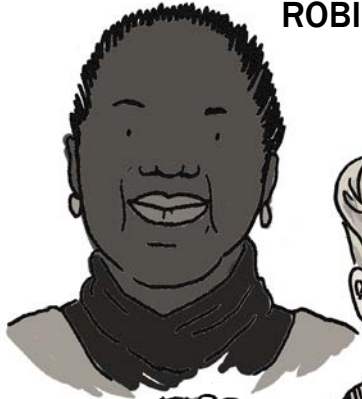
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B&R1

RACISM & TECHNOLOGICAL
INNOVATION IN HEALTHCARE

ROBIN PIERCE



SUZY CAMEY



CARLO
BOTRUGNO



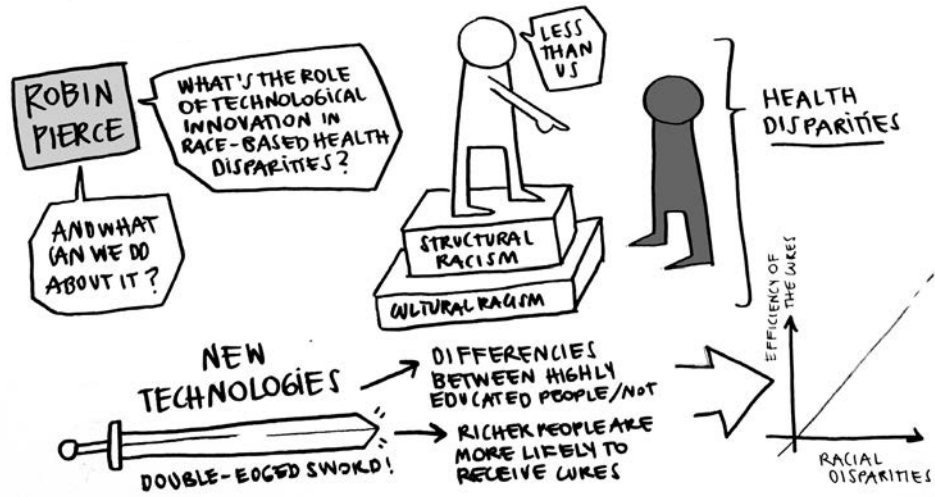
INÊS FARIA



ROBIN PIERCE

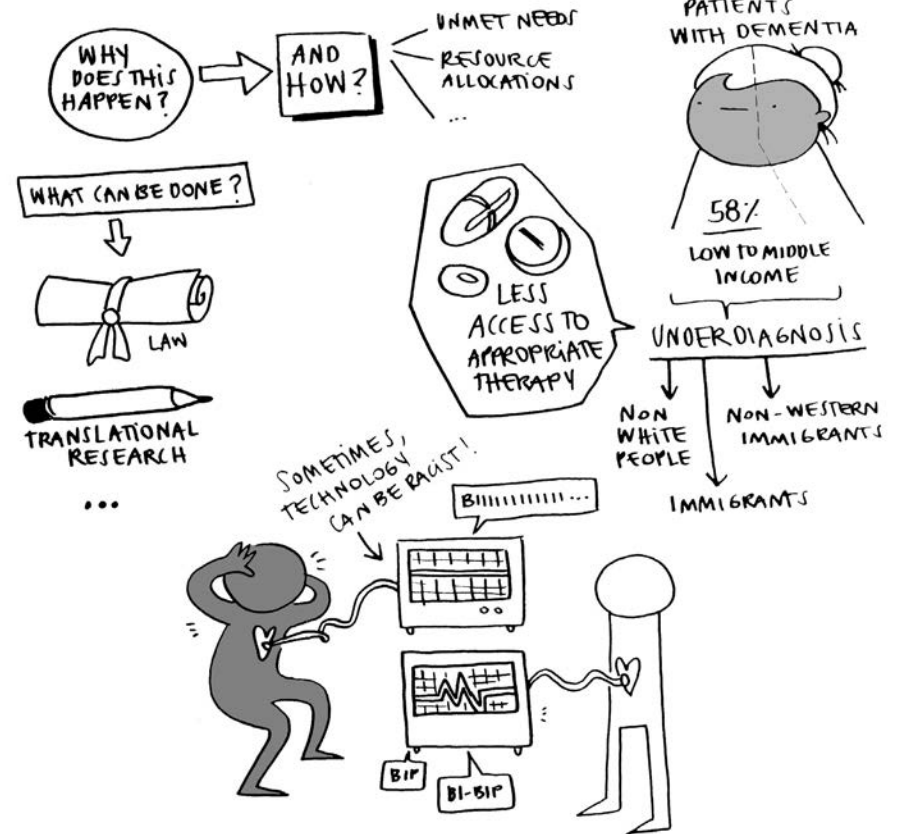
Bias in Technological Innovation in Healthcare: Pursuing commitment to changed practice

Technological innovation in healthcare has long been a force to be reckoned with, though often driven by private interests, wields considerable influence on patient care. From the introduction of to the recent push of AI into the healthcare domain, technology is widely seen to hold the secret to improved outcomes and increased longevity. While the benefits of tech innovation have resulted in improved outcomes of multiple sorts, the degree to which technology confers benefits is not experienced equally across populations. Health disparities along racial lines have been documented for decades, and despite the relentless evidence of health disparities, these disparities persist.



Given the reliance on technology in healthcare, close examination of the role of technology in contributing to or perpetuating inequities in the provision of healthcare is essential. This is perhaps even more pronounced in the digital age when so much of the clinical experience is becoming digitized. This expanded digitization in healthcare also gives rise to new and different ways of contributing to and perpetuating inequities. As healthcare adopts ever more technological resources in the effort to improve health outcomes, the need for scrutiny also intensifies. Yet, the extent to which technology-driven disparities should be addressed by technological solutions is not always completely clear. Looking toward solutions, this paper

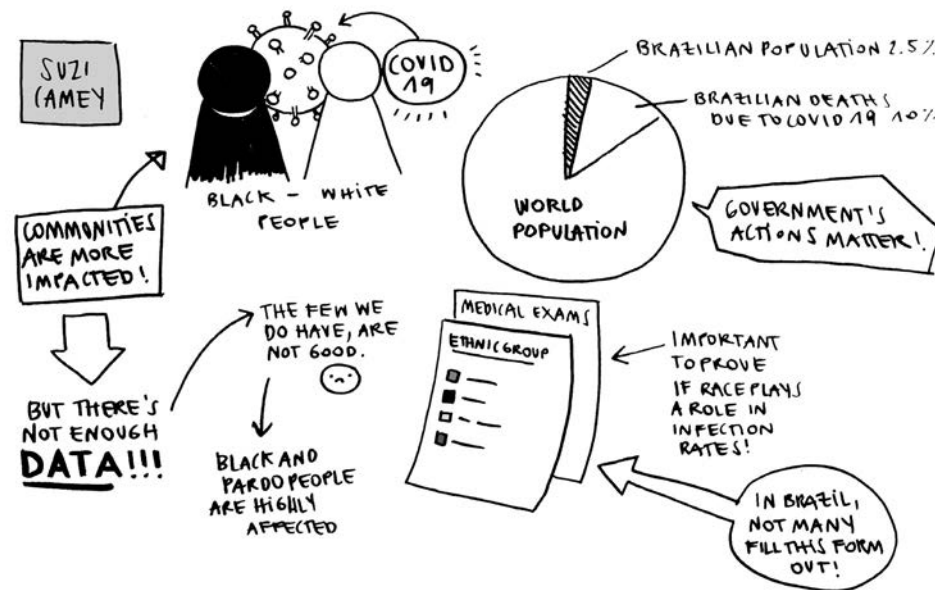
briefly examines the phenomenon of bias in technological innovation in healthcare from the perspective of pathways and promises, and discusses possible approaches to addressing this injustice.



SUZY CAMEY

The disparity between black and white people in COVID-19's numbers

The numbers related to the pandemic are huge. At the beginning of February there are more than 105,000,000 coronavirus cases and more than 2,300,000 related deaths. When we compare the number of deaths about COVID-19 among countries with and without a good response to the pandemic, it could be seen, for example, that in New Zealand COVID-19 would be the 19th cause of death and in Brazil would be the second cause of death when this cause is compared with data from The Global Burden of Disease (2017). Besides the government response, the disparity between black and white people also contributes to differences in death numbers. Although there are plenty of works saying about the necessity of data and special care tagged to black people, there are difficulties to measure and to show these disparities.



For example, in Brazil, there is a law which recognizes the importance of inserting race/color data in health forms. Despite that, most of the states does not provide such information with respect a COVID-19 cases. In fact, only five states show information about race/color in their epidemiological bulletins. Even with a lack of information, a study showed that pardo and black Brazilians hospitalized with COVID-19 had 1.45 times risk of mortality of white people.

It also showed that, after age, pardo ethnicity was the second most important risk factor for death, even before all comorbidities. In the US, the COVID Tracking Project launched The COVID Racial Data Tracker which advocates for, collects, publishes, and analyzes racial data on the pandemic across the United States. Although all states reported data about race and ethnicity, some states, like Texas, report this information for only 3% of cases. The COVID Racial Data Tracker also shows black people have died at 1.5 times the rate of white people.

INÊS FARIA

Therapeutic navigations and assisted reproduction technologies in Mozambique

Departing from the research experience of preparing and doing fieldwork, on therapeutic navigations of Mozambican women in infertile relationships in the quest for a pregnancy in Maputo, my intention with this paper is to question historical colonial legacies and the circulation of global assisted reproduction technologies (ARTs) by focusing on the particular aspect of gender relations, reproduction and racism. In order to do so I will resort to a theoretical framework concerned with the ontological choreographies that take place throughout ART treatments, and with the manifestation of particular ideas, beliefs and practices concerning the notion of race in those processes. This framework will be articulated in the discussion of therapeutic navigations of people trying to have children through ARTs, within landscapes paved by particular by historical, political, and socio-cultural stakes and tensions – in this case regarding Southern Africa (Mozambique and South Africa).



I wish to discuss inclusionary and exclusionary local and global dynamics concerned with reproductive choice, access to ARTs, and ideas about reproduction and female fertility: What kind of rationales about race underly discourses about fertility and infertility in Mozambique, how do these compare to other regions? What are the everyday life intricacies, and the therapeutic and bioethical dilemmas permeating the relationship between demographic assessments of (high) fertility and biographic aspirations to have children? What are the desires of Mozambican women who can access ARTs, what options do they have and consider? How do everyday practices change or reproduce colonial legacies, and how do they help us to unpack these? Rather than drawing any direct conclusions from these questions, my intention is to talk and reflect about them collaboratively. How can research contribute to this discussion, and what anthropology, and cross-disciplinary approaches, should we “practice” to properly address issues of power, racism and technology today?

CARLO BOTRUGNO

Technological determinism and the rhetoric of technological innovation in healthcare

Technological artifacts are often seen as “discrete, value-free” material objects that can be used both for bad and for good. “It depends how you use it”, is a motto that resonates among technology users and providers. I argue that this thought is part of a wider rhetoric of technological innovation, which is deeply rooted in technological determinism and neutrality of science. Over the last two decades, this rhetoric has permeated healthcare, due to the impressive development of information and communication technologies (ICTs) for healthcare or health-related purposes. Digital services have been marketed as a unique opportunity to overcome physical barriers and thus to reduce the extent of health inequalities. According to the European Commission, the implementation of ICTs in healthcare includes a great potential to foster socio-economic inclusion and equality, quality of life, and patient empowerment through greater transparency, access to services and information and the use of social media for health. However, Science and Technology Studies (STS)



showed that technological development does not consist in creating an object that is intrinsically endowed with meaning, but rather it involves the cultural production of new practices, which mediate technology and make it become “technology-in-use”. Research on “social shaping” of technological artifacts played a fundamental role in the reaction to the deterministic-mechanistic view in the field of digital health and surroundings (i.e. telemedicine, telehealth, telecare). STS contributed to the development of a theoretical-conceptual apparatus useful for the understanding of social processes that are implicit in the design and construction of ICT-mediated services in healthcare. This field of knowledge is shedding light on just how much

new healthcare technologies are designed for certain user groups, usually those with higher cognitive and behavioural skills, which are the product of formal education and economic and social capital. Consequently, digital solutions can be easily accessible, amenable, and attractive to some groups while they remain beyond reach for others. From this perspective, it is easier to understand how technological innovation is a matter of justice and equity, and how much national governments and regional authorities must commit to developing a technological agenda that considers discrimination and inequalities in the implementation of healthcare technologies.

B&R2

BIOMEDICAL RESEARCH,
GENETICS AND RACISM



RUQAIYAH YEARBY

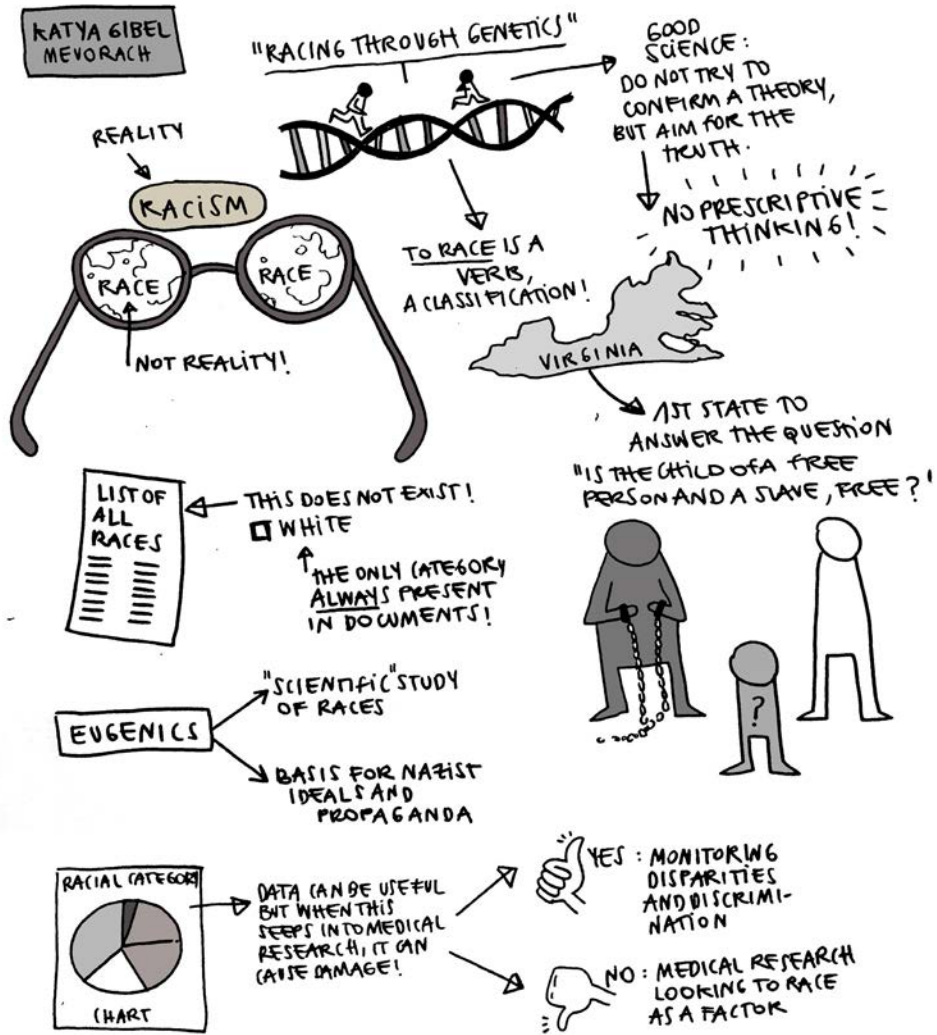
KATYA GIBEL
MEVORACH



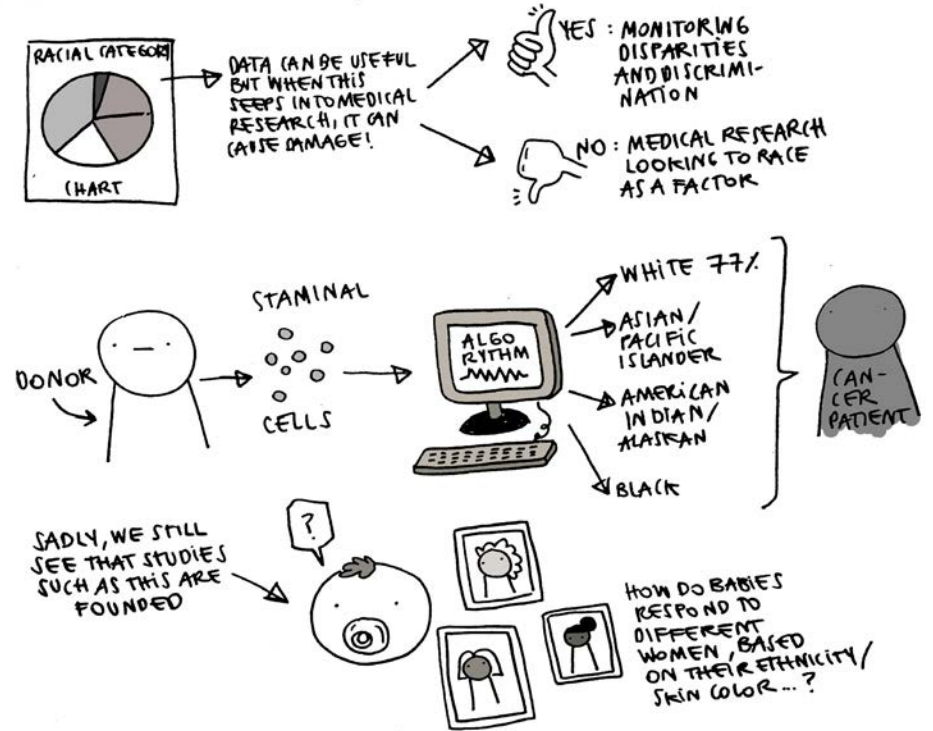
KATYA GIBEL MEVORACH

Strategic Interventions: uprooting racial taxonomy and challenging racism in science courses

My point of departure is the importance of wilful attention to racial taxonomy and the legacy of race thinking in science courses: I will address insights from a course I co-teach with a Biologist which we designed as a strategic intervention against entrenched misperceptions about socio-political categories and human difference. We explicitly challenge our students' (and increasingly our colleagues') understanding of how science has been used to promote ideas about race as biology rather than racism as an action that makes "race" seem like a real entity (the defining characteristic borrowed from Barbara Fields & Karen Fields' *Racecraft: The Soul of Inequality in American Life*). Recognizing that social sciences and humanities are often incidental to science syllabi, we introduce students, many of whom are considering biomedical research and the field of health, to the role that science has played in the construction of race as a system of classifications and ways that these racial classifications are used in the academic and popular arena.



We aim to contribute change in the intellectual pipeline of graduating students and demonstrate that our approach will make them better scientists.

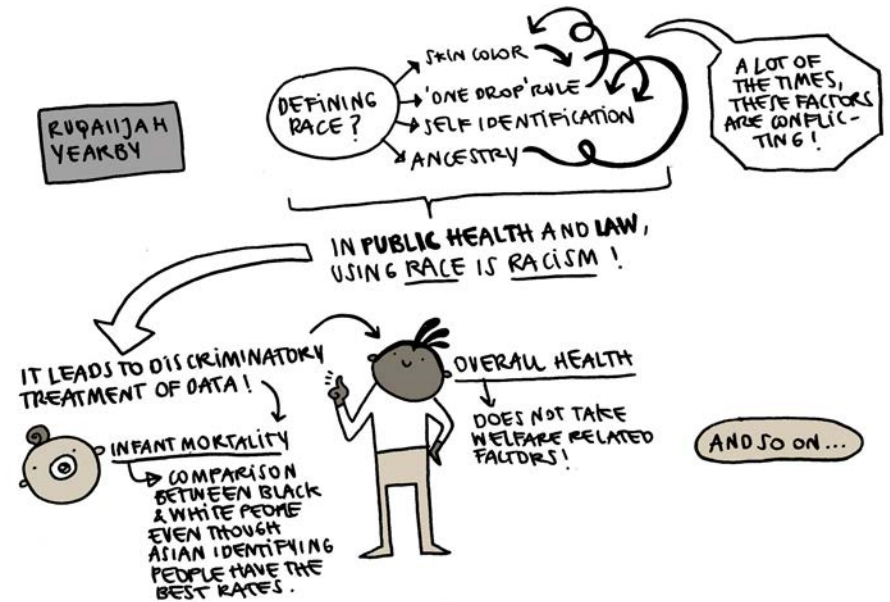


RUQAIJAH YEARBY

Race Based Medicine, Colorblind Disease: How Racism in Medicine Harms Us All

The genomic age showed that the genome between humans was 99.5%-99.9% identical; the 1%-5% variation between any two unrelated individuals was greatest between individuals in the same local population; and there were no identifiable continental or racial genomic clusters. Notwithstanding this evidence, biological race and sometimes ethnicity continue to be noted as factors in health disparities research, medical guidelines, and standards of care.

Most recently, the Journal of Internal Medicine published an article that connected obesity disparities in Blacks with the “unique contributions of physiologic factors related to race” which was rightly challenged because the researchers claimed that unspecified genomic racial differences linked to skin color caused these unique contributions to Blacks’ physiologic differences. Thus, even though there are no identifiable racial genomic clusters, race continues to be misused as a biological reality in health disparities research, medical guidelines, and stan-



dards of care to reinforce the erroneous notion that racial and ethnic minorities are inferior to Whites. This presentation discusses how the continued misuse of race in medicine and the identification of Whites as the control group, which reinforces this racial hierarchy, are examples of racism in medicine that harm all us.

*SICKLE CELL → AFFECTS PEOPLE FROM MANY COUNTRIES

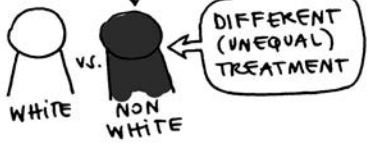
BUT

SEEN AS A "BLACK DISEASE"



ALSO: COVID 19 PULSE OXIMETER BREAST CANCER

- NO FUNDING FOR RESEARCH
- PEOPLE FROM OTHER ETHNIC GROUPS ARE NOT TESTED FOR IT



ALL OF THIS DERIVES FROM ...

IDEOLOGY OF INFERIORITY



B&R3

RACISM IN HEALTHCARE



CLAUDIO
LORENZO

JOSIMARIO SILVA



CARLO
BOTRUGNO



LUCAS MENDES
DE OLIVEIRA



MARCIA
MOCELLIN
RAYMUNDO



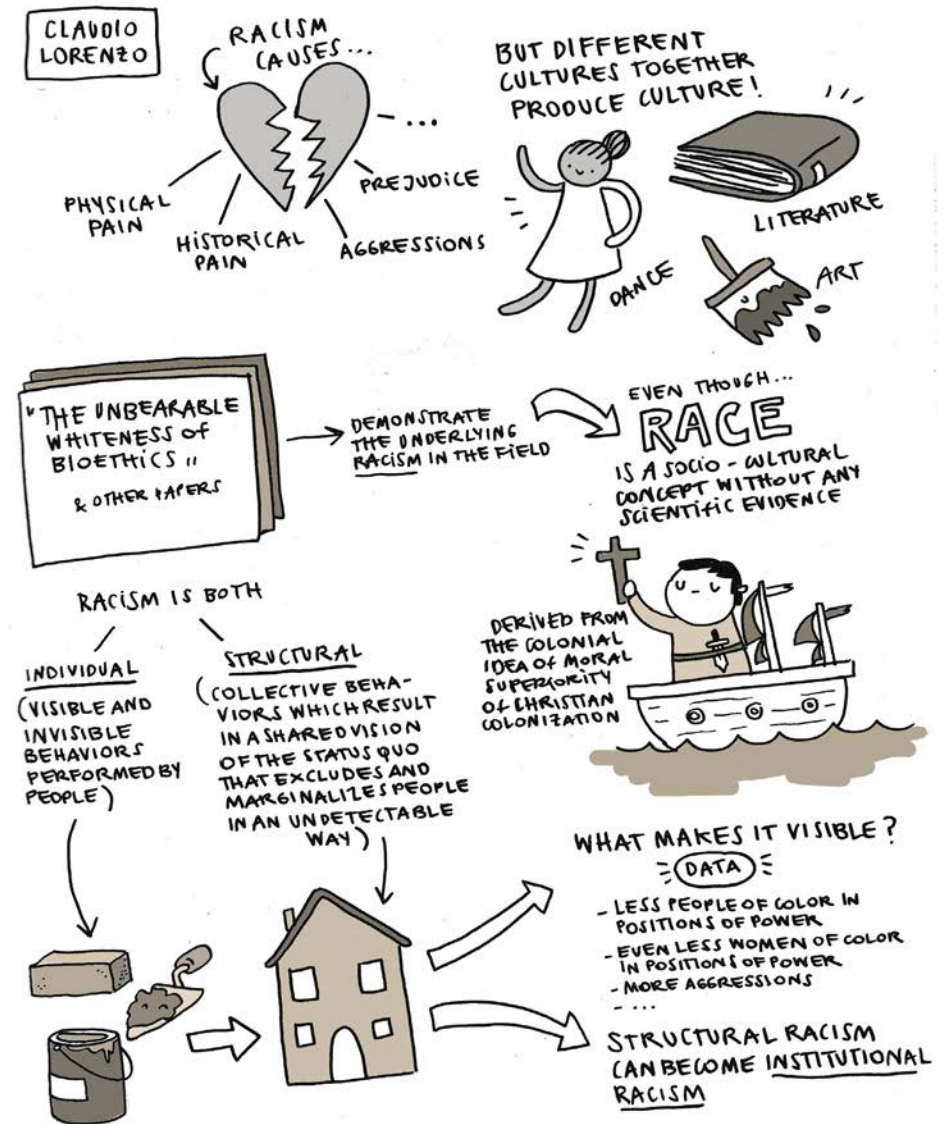
CELIA MARIANA
BARBOSA DE SOUZA



CLAUDIO LORENZO

Racism in Health Care

I intend to analyze racism in health care based on concepts of race and racism produced by contemporary black thought, and taking into account three levels of racism: structural, institutional and inter-relational. Based on the Brazilian reality, I will approach racism as a determinant in health. After that, I will present a brief overview of race-based health inequalities, and I will discuss its impact on institutions, health practices and inter-subjective relationships in healthcare. I will refer to real examples for this, such as the assistance to young black people with sickle cell anemia, or obstetric violence against black women. Moreover, I will address the importance of public policies to combat racism, filling in health data based on the race-color item, and anti-racist education in the training of health professionals.





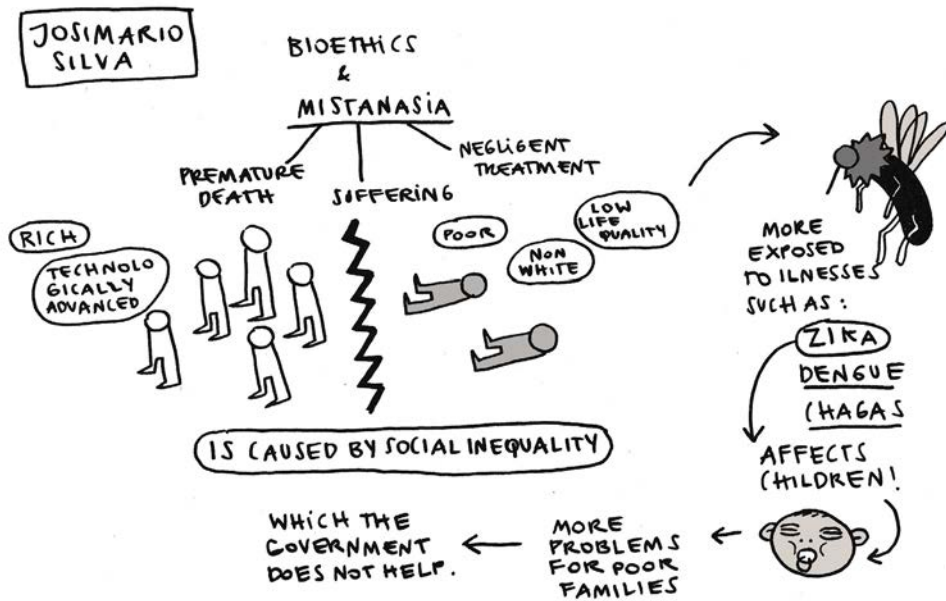
Finally, I will analyze the impact of the Covid-19 pandemic on the health of the black population, and the Brazilian political context of explicit racism and the dismantling of social programs and policies, as well as the harmful political alignment to the current government of important social organizations with influence in health practices like the Federal Council of Medicine.

JOSIMARIO SILVA

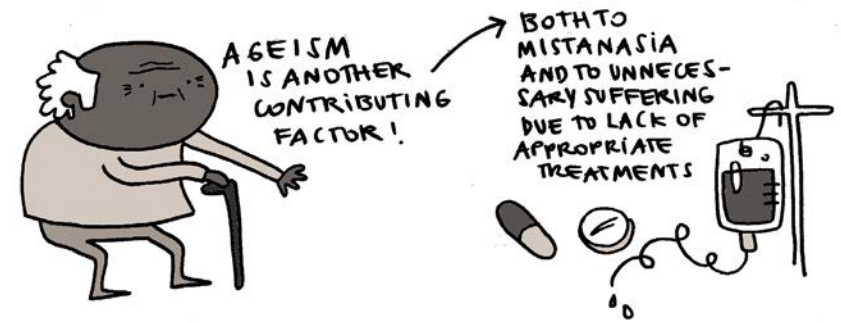
Bioethics and mysthansia: A cruel face of human indignity

Human Health, being analyzed in a bioethical point of view, can be considered as an intangible heritage of humanity, considering that it needs to be protected and recognized as an inalienable asset, respected in beliefs, values and traditions, receiving all the necessary conditions for its maintenance and perpetuation of the species for future generations. Considering that the human being is inserted in a society, it is the role of the Democratic State of Law, to promote all the conditions that promote human dignity, among them is the access to decent education, health, safety, work, leisure, among other rights already legally established in the country's federal Constitution. The denial of these constitutionally defined and ratified rights in the 1988 federal Constitution, is a devaluation, that is: it is the deprivation of access in a dignified way, of the system that was legally elaborated by popular participation for human protection and that without this protection system, the citizen will have their biological and social vulnerability enhanced, resulting in the vast majority of times in early, unassisted, undignified and inhuman

deaths. It is in this scenario that mysthanasia is installed. Mysthanasia is a term of Greek origin used to give meaning to the death of people without any social representation. Poor, black, vulnerable people are often not seen in their dignity as human beings of rights and respect.



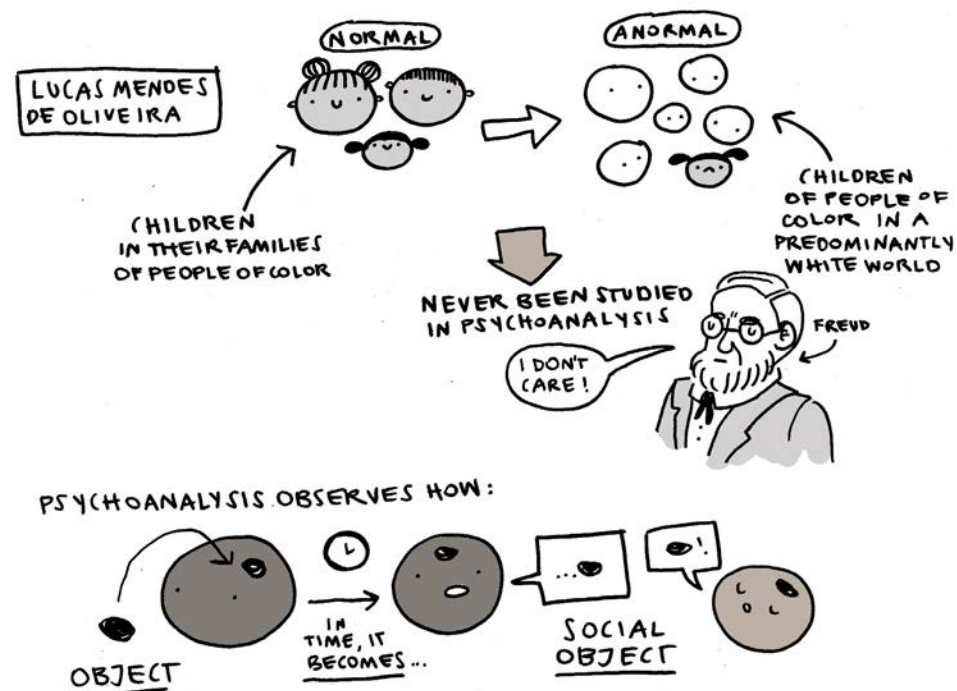
Most of the people in Brazil's prison system are black, poor and with little formal education. People who die in queues waiting for a vacancy in the ICUs, the vast majority are vulnerable people by social condition, by skin color, by lack of formal education. Today many patients admitted to public hospitals are not properly treated because the state system does not provide conditions for dignified professionals so that they can provide the most appropriate care possible for patients. They are people who have no social status, many miserable by endemic poverty, so mysthanasia despite not being much spoken or known is a cruel face of human indignity.

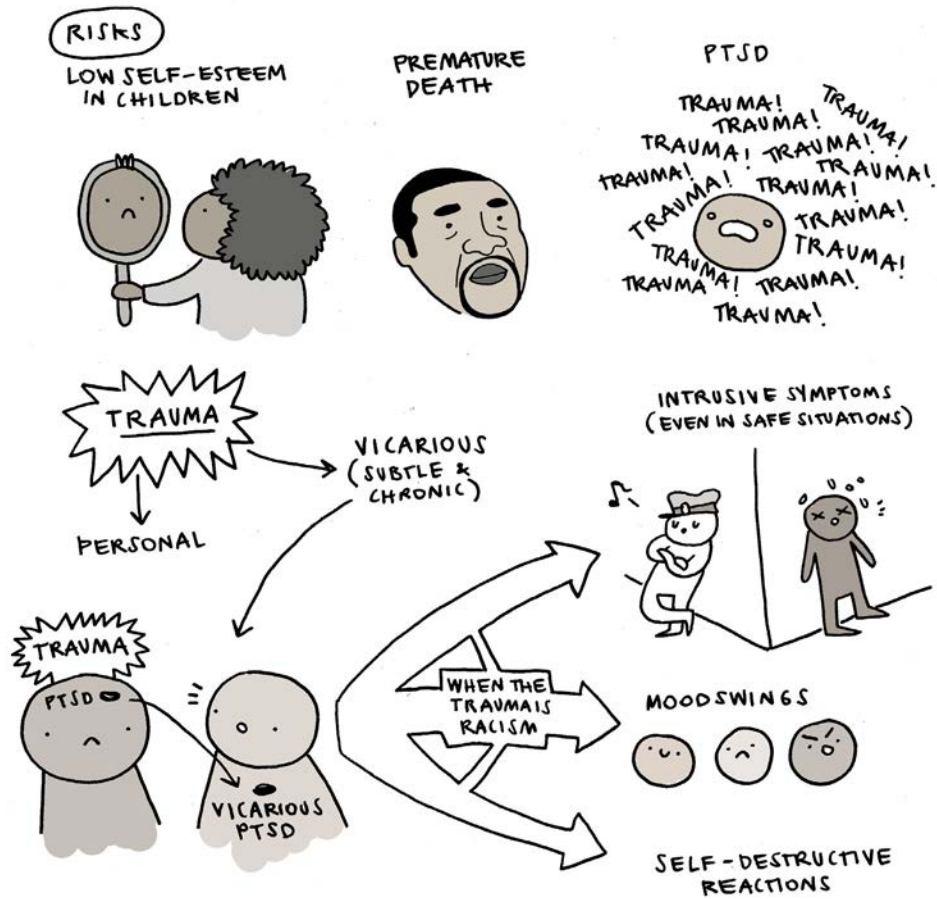


LUCAS MENDES DE OLIVEIRA

Racism, a vicarious traumatization model

Racism is a structural social phenomenon that significantly impacts on mental health of black populations. That's not new information although commonly, in Brazil, discussions about racism often focus on explicit examples of racial aggressions, which leads to a simplification of the possible structural interventions. As structural phenomena, racism is always working at an unconscious level. At the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) trauma is defined as "experiencing or witnessing a life threatening experience". A trauma specifier is Vicarious Traumatization, defined as "the recurrent exposition to aversive details of the traumatize event". Racism can be understood as an unconscious life threatening vicarious event. Some common psychic reactions of black people as neglecting, low self esteem, depressive mood, aggressive reactions, avoidance behavior, social isolation, are very similar to the symptoms described in vicarious traumatized patients.





So, following this model, if we consider, as example, white skin as one of the aversive details of the trauma, many times the presence of a white skin person is capable of starting this unconscious trauma reaction. In health care patient-professional relationship, the skin color is an important component of the bonding process. If white people do not have the knowledge about the unconscious impacts of their skin color, it's harder to be aware of the subtle aspects of the bonding process. I believe that this vicarious traumatization model is useful to help health professionals to understand and become more capable to prevent compromising negative behaviors racial related. At a collective level, the process pass by bringing up to consciousness the unconscious negative imprints of racism and then become able to reframe this bad aspects of black identity, history, and culture, into real and positive ones.

MARCIA MOCELLIN RAYMUNDO

Bioethics, racism and human rights

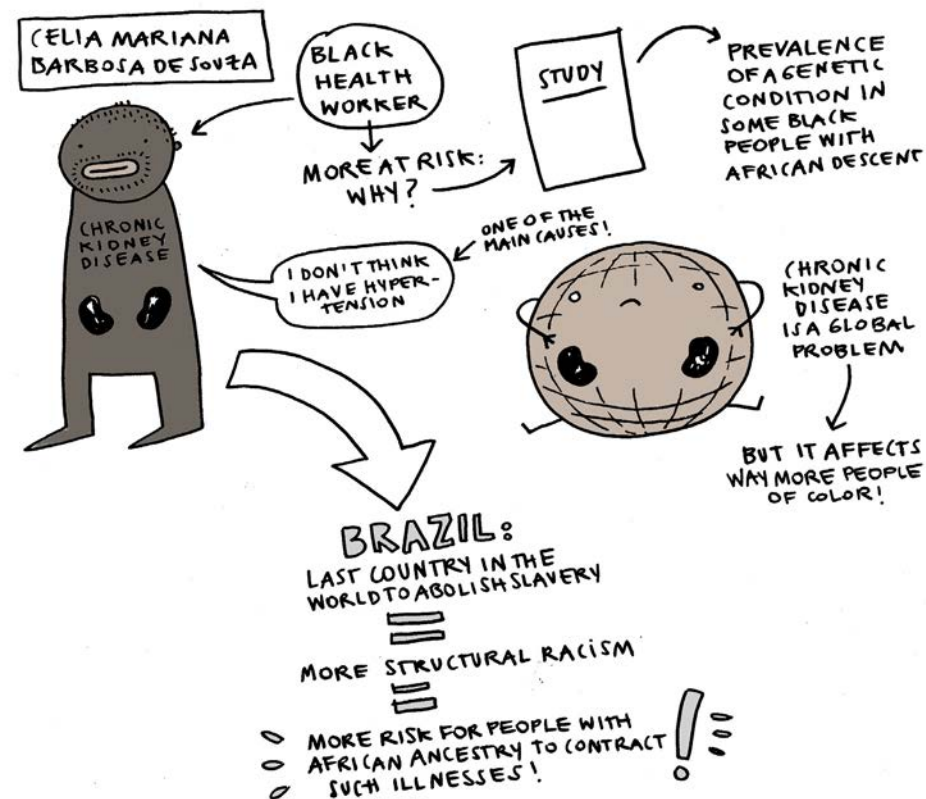
Bioethics – considered an interdisciplinary field for its intercultural attitude and its proposal as “ethics of life” – presents sufficient characteristics to address various themes related to human relations, including racism issues. Although historically bioethics has become recognized for its approach to issues related to biomedical advances, with greater emphasis on individual interests, some issues related to collective interests are of utmost importance within its universe. Diversity, citizenship and the environment are examples of issues that can – and should – be approached from a bioethical perspective. In this sense, there are many challenges to bioethics today, and among them are different aspects involving racism. Bioethics and human rights are essential references when it comes to addressing issues related to health care for diversity, as they can not only help in the understanding of potential conflicts or dilemmas that may arise, but also propose appropriate approaches for their resolution. This approach can help in the understanding of different attitudes towards the same fact, common to all human

beings, such as birth and death, whose specificities vary in different cultures. The fact that there are differences around these phenomena, with particularities in each culture, does not mean that one is right and the other wrong, it means that there are differences. Although seemingly simple to understand, many healthcare professionals have great difficulty to understand and respect different cultures apart from their own. It is precisely in this kind of situation that bioethics, together with the human rights framework, can contribute to conflict resolution, mainly due to the ability to support coexistence, citizenship and human rights policies required by interculturality, besides encouraging respect in different worldviews.

CELIA MARIANA BARBOSA DE SOUZA

Prevalence of Risk G1/G2 genotype of APOL1 gene in association with Chronic Kidney Disease in non-diabetic self-declared black individuals

Chronic kidney disease (CKD) is a public health problem throughout the world. In Brazil, it is estimated that 10% of the population has the disease. Individuals of African descent develop CKD, especially end-stage kidney disease associated with systemic arterial hypertension, at a rate 4 to 5 times higher than people without African descent. Recent studies show that mutations in the APOL1 gene located on chromosome 22q, near to the MYH9 region, appear to have three times the effect of MYH9 gene in terms of risk for nephropathies. The APOL1 gene is present in approximately 30% of African Americans, but is not found in white individuals. These studies have shown that blacks with the two G1 and G2 risk alleles of the APOL1 gene are more susceptible to developing chronic non-diabetic kidney disease than blacks with only one or no risk alleles. In Afro-descendants with both G1 and G2 alleles, the increased risk for primary segmental and focal glomerulosclerosis and HIV-associated nephropathy is



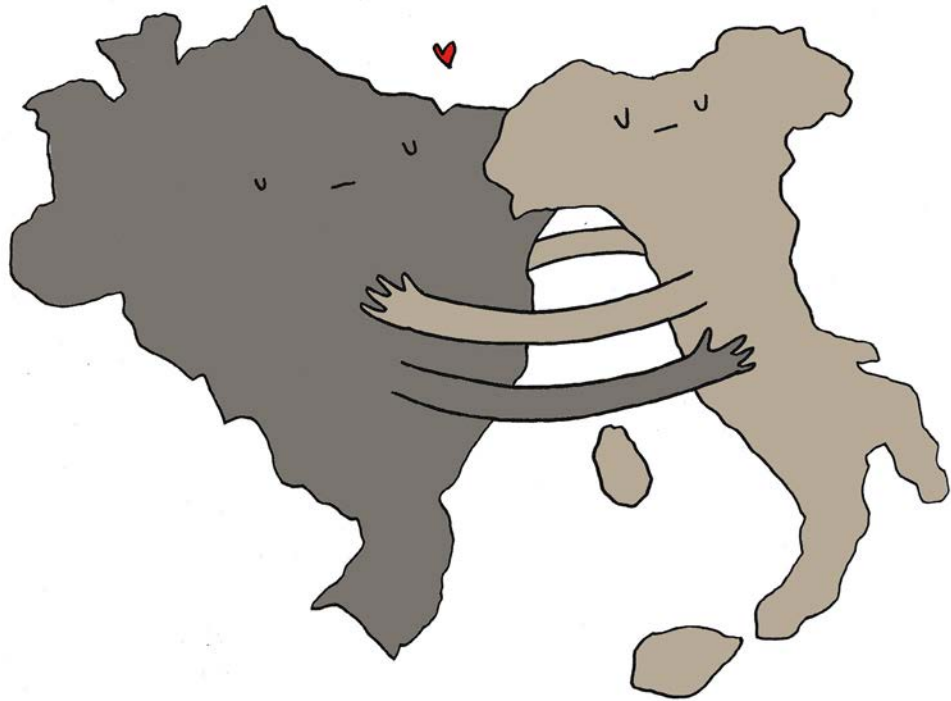
17 and 29 times, respectively, in which the disease develops at an earlier age, has faster progression and confer less long-term renal survival. The history of black population in Brazil is marked by inequality and resistance to slavery. Its arrival in Brazil started in the XVI century from the African continent to work in crop and plantation of sugar cane during the colonial period. Prevention actions of CKD in black individuals should involve knowledge of these risk factors, as these individuals are exposed to earlier illness and have a higher rate of progression to the final stages of CKD, requiring renal replacement therapy with dialysis or transplantation. Thus, the primary objective of this study is to determine the prevalence of the high risk G1 + G2 genotype of the APOL1 (combined) and low risk (G1 or G2 isolated, or neither) gene in patients with African descent who are diagnosed with CKD associated with systemic arterial hypertension, and primary non familial segmental and focal glomerulosclerosis, compared to healthy afro-descendant individuals.

CARLO BOTRUGNO

How much does the difference weigh in healthcare?

My talk from the “everyday bioethics” approach, and aims to assessing the “weight of the difference” that currently overwhelms migrants in both maintaining psychophysical wellbeing and accessing adequate healthcare services in host countries. I outline the main risks for migrants’ health during their transit, as well as the main obstacles usually preventing them from accessing adequate healthcare services in receiving countries. I then elaborate by trying to shed light on the association between people movement and the spread of infectious diseases, which arguably represents the core of current political debate and tensions over international migration flows. Thereafter, I continue by looking at the interplay of detention, migration and healthcare, in which both illegal and legal migrants are often entrapped because of their intrinsic precarious conditions. I will then highlight the main challenges associated with socio-cultural misconceptions in health and healthcare that exacerbate health inequalities to the detriment of migrant people. In the conclusions, I build on the everyday bioethics approach to underscore

how it can contribute to both bioethics debates and the attempt to enhance the protection of migrants' health.



B&R4

RACIST AND ANTI-RACIST
PRACTICES AND POLITICS



DJAMILA RIBEIRO



LUCIA RE

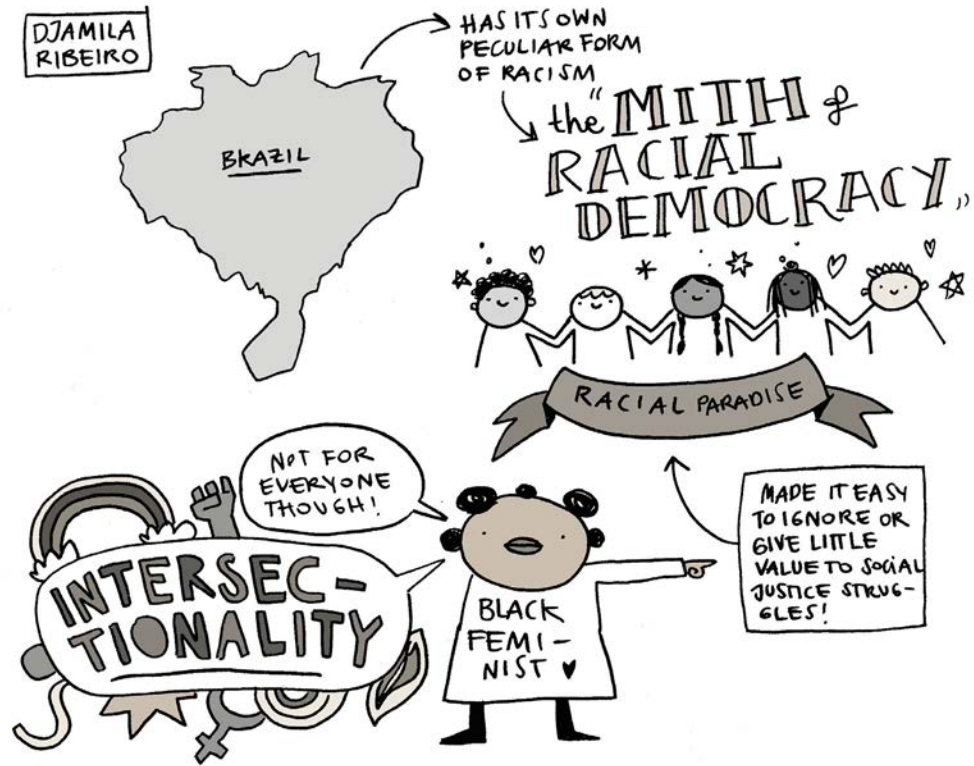


EDUARDO RUEDA

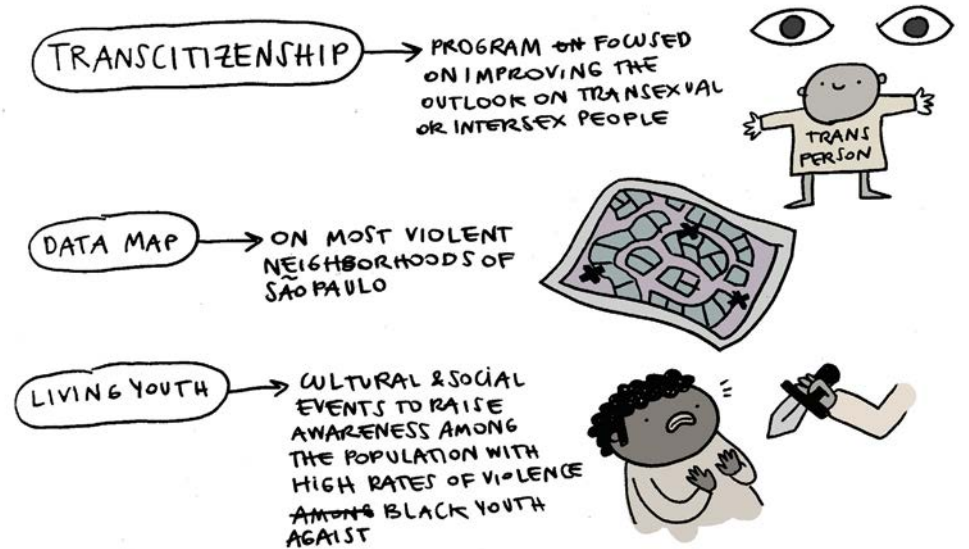
DJAMILA RIBEIRO

Racist and anti-racist politics and practices

“We are not born black, we become black. It is a hard and merciless struggle that goes on for a lifetime”, said the black feminist Lélia González. We are born as a body in a web of meanings over which we have no control. The black person’s identity is not a ready or a finished product, and an awareness of their own blackness is important for the building of anti-racist practices, but cannot be the only determinative factor as a reaction against racism. In other words, beyond the awareness of how groups of identities are articulated by power in places of privilege or invisibility. Such social groups, each from their own starting point in society, as an ethical duty, can have an impact on policies that deal with structural oppression of race, class and gender. Facing a structure of such magnitude requires structural changes that must be put into practice. In this sense, at this meeting, I intend to address ways of theoretical and practical reflection of black feminism for those who want to deepen their perception of structural racial discrimination and take responsibility for the transformation of the state of things.



The perception that racism is deep-seated in our society has been solidifying for many years, creating inequalities and social gaps: it is a system of oppression that denies rights, and not an individual's simple act of will. Recognizing the roots and impact of racism can be petrifying. After all, how can we face a monster this big? Anti-racist practice is urgent and occurs in the most mundane gestures. And what's more: it is everyone's struggle



EDUARDO RUEDA

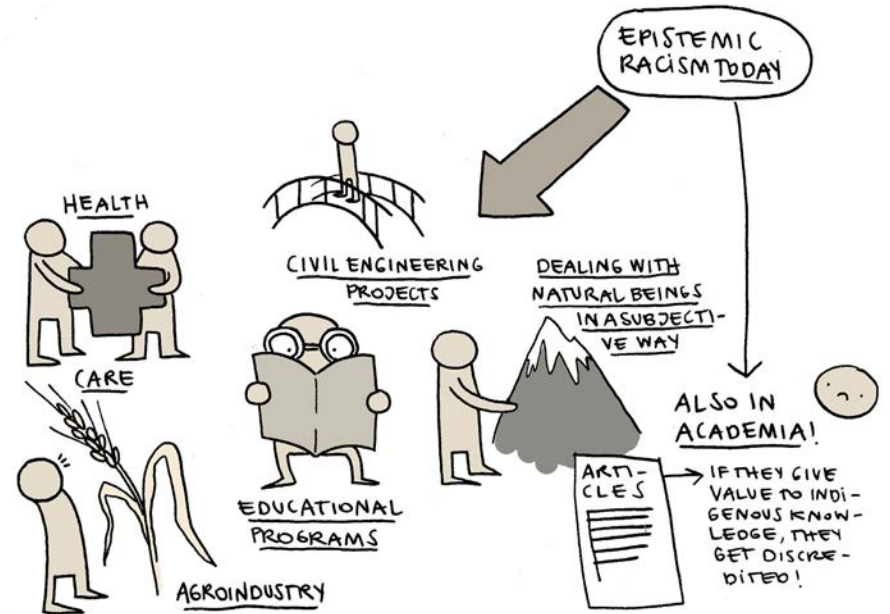
Epistemic Racism

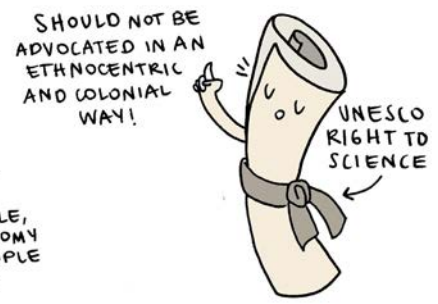
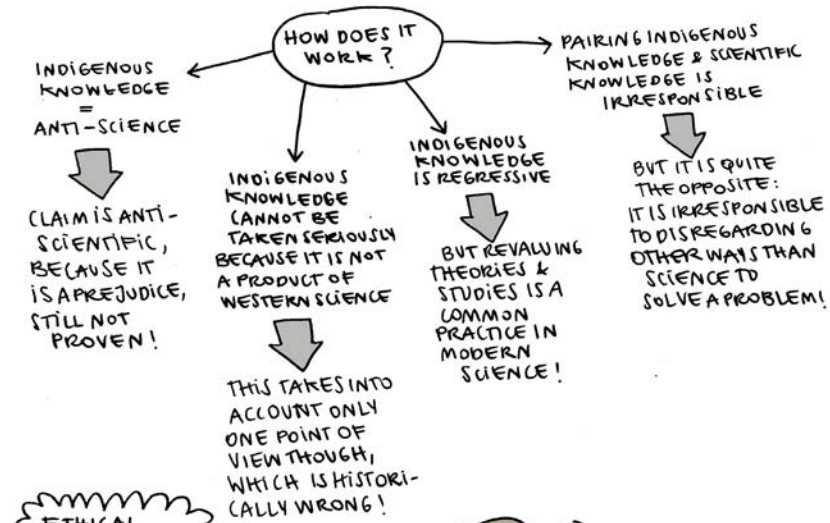


The presentation addresses the problem of epistemic racism in three steps. Firstly, and after make a case on what is racism and why epistemic segregation constitutes a form of racism, the presentation considers the problem from a postcolonial perspective, disclosing, in a general way, the historical roots on which it was settled and naturalized. To do that the presentation explains, by giving two crucial examples, how the “colonial device” configured the meaning and social uses of both nature and wellbeing and how that reconfiguration reshaped the meaning, spatiality, and authoritativeness of knowledge itself. Along this very brief “decolonial” reconstruction, the presentation shows how the entanglement of ‘progress’, disenchantment of nature and “development” worked out to naturalize and ‘sediment’ epistemic exclusion of both non-western populations and non-white male gender. Secondly, by analyzing some recent conflicts between different groups of scientists in Latin America regarding the epistemic value of indigenous knowledge, the presentation characterizes and criticizes the underlying presump-



tions of epistemic devaluation. Finally, the presentation explores the ethical implications of this kind of racism. Firstly, from a human rights perspective the presentation points out the consequences that this form of invisible and naturalized racism has had in political rights of affected populations as well as the individual autonomy of their members. Secondly, the presentation discusses why overcoming epistemic racism becomes crucial to accomplish moral duties toward both future generations and environment.

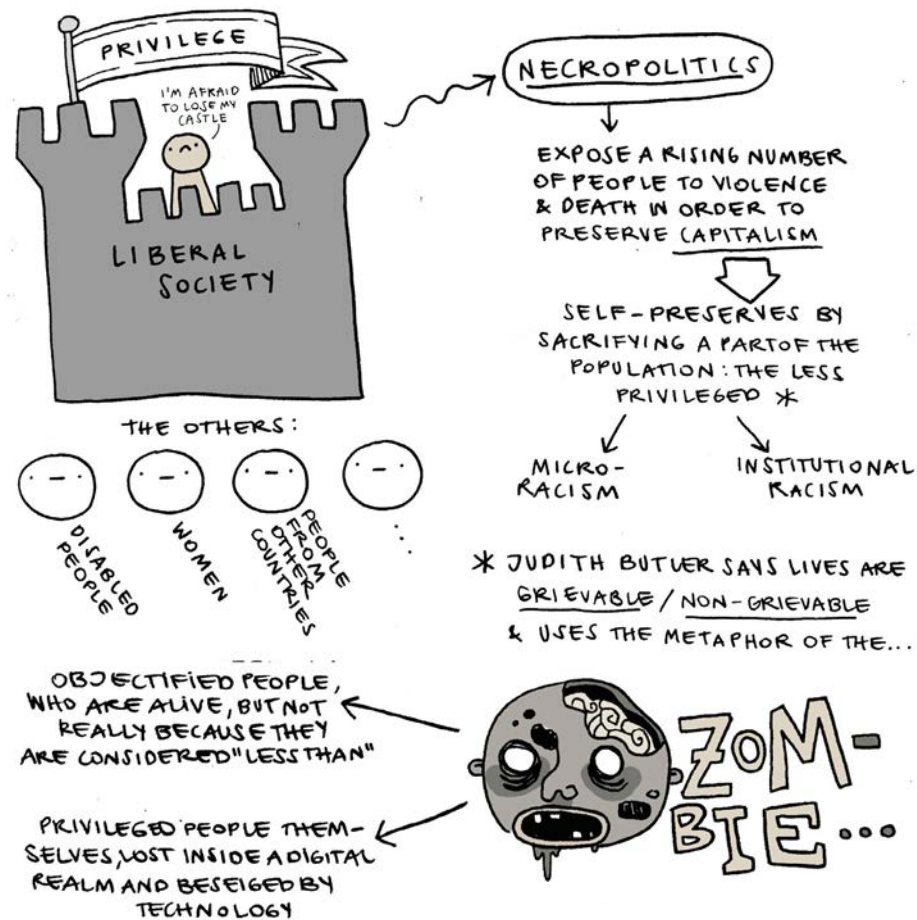
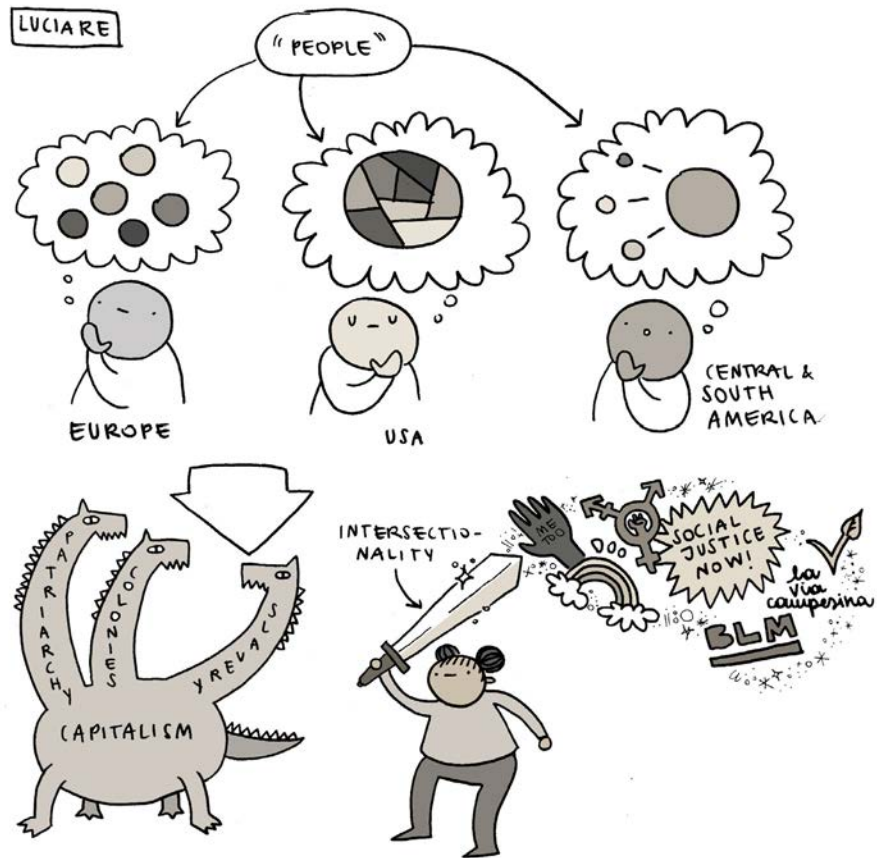




LUCIA RE

Necropolitics, racism and migration management

Starting from Achille Mbembe's analysis on "necropolitics" and the function of racism in contemporary societies, the paper frames European migration policies in a postcolonial perspective, analyzing them in the light of the paradigm of "exclusive citizenship" identified by Emilio Santoro. The consolidation of a hierarchy based on differentiated legal statuses – a sort of "globalization of the code of the indigenous" – seems to be the goal of a deeply violent system of management of racialized populations both in the South and in the North. Mbembe has spoken of the migrant body as a "frontier body" that it is forbidden to host or protect, to save from drowning on the high seas or from dehydration in the middle of the desert, a "frontier body" and a "prey body". Hunting, however, does not seem to aim so much at annihilation for its own sake as at the selection and precarization of the existences of those who manage to cross the borders, an "inclusion through illegalization", which makes it possible to achieve what Sandro Mezzadra has called a "differential inclusion".





ALSO EVIDENT IN THE E.U. WHERE IMMIGRANTS STRUGGLE TO BECOME CITIZENS, THUS LIVE WITHOUT ALL OF THE RIGHTS THEY SHOULD HAVE AS HUMAN BEINGS

