Equality, equity, and justice in health in the light of bioethics

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Abstract

The *Universal Declaration on Bioethics and Human Rights* enabled the reflection on themes that go beyond purely biomedical concerns and address social, health and environmental topics such as social exclusion, vulnerability, poverty, and discrimination. This article aims to reflect on the concepts of equality, justice, and equity, as defined by the *Declaration*, and their applicability in solving health problems in Brazil. From a bibliographic review, both classic (Plato and Aristotle) and contemporary (Amartya Sen, John Rawls, Paulo Fortes and Fermin Schramm) authors were addressed. The study proposes equity as a principle for critically understanding health policies and services, helping citizens to act with social responsibility.

Keywords: Bioethics. Human rights. Civil rights. Equity. Health.

Resumo

Igualdade, equidade e justiça na saúde à luz da bioética

A *Declaração Universal sobre Bioética e Direitos Humanos* viabilizou a reflexão sobre temas que ultrapassam a relação biomédica e abrangem questões sociais, sanitárias e ambientais, como exclusão social, vulnerabilidade, pobreza e discriminação. Este artigo tem como escopo refletir sobre conceitos de igualdade, justiça e equidade, como definidos pela Declaração, e sua aplicabilidade na solução dos problemas de saúde no Brasil. A partir da revisão bibliográfica foram retomados tanto autores clássicos (Platão e Aristóteles) como contemporâneos (Amartya Sen, John Rawls, Paulo Fortes e Fermin Schramm). O estudo propõe a equidade como princípio para a leitura crítica das políticas e serviços de saúde, instrumentalizando cidadãos e cidadãs para agir com responsabilidade social.

Palavras-chave: Bioética. Direitos humanos. Direitos civis. Equidade. Saúde.

Resumen

Igualdad, equidad y justicia en contexto de la salud a la luz de la bioética

La *Declaración Universal sobre Bioética y Derechos Humanos* posibilitó la reflexión sobre temas que sobrepasan la relación biomédica y que envuelven cuestiones sociales, sanitarias y ambientales, como la exclusión social, la vulnerabilidad, la pobreza y la discriminación. Este artículo tiene como objetivo reflexionar sobre los conceptos de la igualdad, la justicia y la equidad según se definen en la Declaración, así como su aplicabilidad para la solución de los problemas de la salud en Brasil. A partir de una revisión bibliográfica, se recuperaron tanto a autores clásicos (Platón y Aristóteles) como contemporáneos (Amartya Sen, John Rawls, Paulo Fortes y Fermin Schramm). El estudio propone la equidad como principio para la lectura crítica de las políticas y servicios de salud y como medio de proporcionar herramientas a los ciudadanos y ciudadanas para que actúen con responsabilidad social.

Palabras clave: Bioética. Derechos humanos. Derechos civiles. Equidad. Salud.

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The expansion of the field of bioethics that occurred in the last 40 years allows currently applying its precepts to discuss comprehensive social and political problems related to the well-being of individuals, peoples, and nations, and narrower issues, that affect the citizens' knowledge and actions in their daily lives, not only in public health, but also in other essential areas [1].

This article starts from the *Universal Declaration on Bioethics and Human Rights* (UDBHR) [2] to reflect on how the concepts of equality, justice, and equity apply to health issues in Brazil [1,3], discussing them not in an abstract manner, but rather in the context of social issues currently addressed by bioethics. It is intended to analyze, in a country like Brazil, what are the possibilities of ensuring equal treatment to individuals with such unequal social insertions, thus contemplating the excluded people, in the condition of "social apartheid," [4] who are disregarded in their most basic rights.

This study also engages with several authors who already proposed similar questions. After all, how can we guarantee equity in a country like Brazil [5]? When inequality is preventable and unfair, turning itself into inequity, what course of action should be taken [6]? How can bioethics reveal oppression and injustice in the health area [7]? Is it possible to treat unequal people differently, according to their needs, to reduce inequities [8]? Finally, thinking in concrete and practical terms, how to guarantee the success of the Unified Health System (SUS) regarding resource scarcity [9]?

Here, a debate is established assuming that bioethics, defined as ethics applied to health and human life, is closely connected to the ideas of justice, equality, and equity. In the inter and transdisciplinary transit [10] between fields such as philosophy, political science, history, art and collective health, this research seeks to elucidate these three concepts, addressing both classical (Plato and Aristotle) and contemporary authors (Amartya Sen, John Rawls, Paulo Fortes, and Fermin Schramm).

In Brazil, the major equality and sanitary justice milestone – essential principles to achieve the notion of equity – is the Federal Constitution of 1988, which in its article No. 196 establishes health as *a right of all and an duty of the State and shall be guaranteed by means of social and economic policies aimed at reducing the risk of illness and other hazards and at the universal and equal access to actions and services for its promotion, protection and recovery* [11]. Unequivocally, the *Magna Carta* expresses an idea of justice that contemplates every citizen, seeking to guarantee the universality of access to health care, broadly understood as well-being, in addition to hospital medical care.

However, the question already posed by Siqueira-Batista and Schramm still remains: *would justice as equality really be possible*? [12]. The chances are small. The principles in question, of solidarity and equality, are based on the assumptions of socialist and welfare states, which since the 1970s have been supplanted by neoliberal policies of austerity and downsizing of the state machine, including the health field [13].

Regarding access to healthcare services, the Brazilian situation is unfavorable. By institutionalizing universality and equality as principles, SUS formally reduced social exclusion. However, inequity still persists, fueled by misinformation, the absence of public policies and all sort of privileges and discrimination [14]. This scenario could not be any different, considering the extreme socioeconomic inequality [15] that affects users' accessibility and healthcare itself.

Although there is still much to be done before healthcare becomes accessible to all Brazilians, advances in this direction should not be disregarded. For instance, the Decree No. 7.508/2011 [16], which regulates the implementation of Law No. 8.080/1990, is fundamental for constructing a system effectively characterized as a right of all and a duty of the State. This decree was an important step to guarantee a legal framework, and represented a breakthrough compared with other Ibero-American countries such as Portugal [17], Colombia [18], and Chile [19], which have regressed in the duty of ensuring the right to health. This setback results from the application of neoliberal market-based models at the expense of values such as solidarity and equity, which are essential to achieve social justice [17].

However, despite advances in Brazil, the role of the State has also been reduced. This mitigation, aggravated by the recent global financial crisis and broadly discussed by addressing the social determinants of health [20], raises a pressing need for alternatives to face social problems often neglected by the market. These questions are complex, and this article does not claim to answer them definitively. Rather, it aims to discuss, from the defined epistemological perspective, relevant aspects of the theme from a bioethical perspective.

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Equality, justice, and equity: epistemological cuts

Using the meanings of equality, justice and equity can help to clarify why these terms are so used nowadays. This is, in fact, the resumption of notions that have long helped human beings understand their political context. In particular, these three concepts are tools for reflecting on the complex reality of public policies [3] and their insufficiency in combating extreme poverty [21] that afflicts much of the world, especially a significant portion of the population of the so-called "developing countries."

These concepts are considered here in their historical and social complexity. The notions of equality and justice, for example, refer to the Hellenic world and the establishment of political activity in the West. The Greek polis constituted itself on ensuring equality between citizens before the law, although excluding slaves and women from the political process [22]. Plato, in *The republic* [23] and *Gorgias* [24], deals with the idea of justice in a singular way. For him, fairness is to fulfill each one's own duty, and a society is fair if there is justice for all who belong to it [23].

Among ancient philosophers, it was certainly Aristotle [25], Plato's disciple, who dealt more systematically with ethics, and especially justice and equity. The philosopher defended equality between men, with each person meeting their own needs – with the caveat that this equality took place at hierarchical levels. Thus, those considered less human, such as slaves, would be excluded from the standards considered fair for the other citizens .

Aristotle considers justice an elementary virtue for an orderly and conflict-free society, the first condition for a happy life: *Justice is the bond of men in States; for the administration of justice, which is the determination of what is just, is the principle of order in a political society* [26]. It starts from the realization that *all men mean by justice that kind of state of character which makes people disposed to do what is just, and makes them act justly and wish for what is fair* [27].

The problem is that, for Aristotle [25], there are two dispositions in man for the same definition of justice, that is, two different forms of justice – hence the need to differentiate them and understand how they relate. Legal justice refers to the willingness to respect everything that is determined by law; particular justice, is the willingness to have neither more nor less than is due [25]. The latter refers to an important principle to do justice: equality, in the sense that each one receives proportionally to their worth.

Thus, we arrive at the notion of justice as equity, duly supported by the Aristotelian notion of corrective justice, which rectifies failures that create injustices to meet each one according to their needs, even transcending legal aspects. It is about wishing, pursuing and achieving maximum equality in relationships, ensuring individually the fair measure of what one should have [25].

In the Aristotelian perspective, equality can never be absolute, since in the relationship between unequal parts the distribution of goods must also be uneven. According to the philosopher, the just *must be, at the same time, intermediate, equal, and relative; as an intermediary, one must avoid certain extremes; as equal, it involves two equal participations* [28]. If people are not equal, they should not receive equally.

The ethics of the virtues, depicted here by Aristotle, presents essential notions, to some extent still current, but which are insufficient to respond to the complexity of the social and political issues of the contemporary world. Thus, it is worth highlighting John Rawls's thoughts, an indispensable author of political theory, especially for his works *Political Liberalism* [29] and *A theory of justice* [30].

Rawls [30] understands justice not as a result of the interests of all, or of the majority, but as a fundamental deontological assumption to perceive collective desires. His democratic thinking is based on two concepts: first, what he calls "original position," a hypothetical situation in which free and equal people choose, under the veil of ignorance, the principles of justice that must govern the basic structure of society; second, the "well-ordered society", regulated by a political and public conception of justice, accepted by all, under the equitable terms of social cooperation.

According to Rawls [30], the principles for building a just and democratic society are: 1) each person has the right to an adequate scheme of basic liberties, as long as it is compatible with the guarantee of an identical scheme for all; and 2) social and economic inequalities are only justified if they are linked to offices and positions open to all, under equal conditions of opportunity, or if they occur for the greatest possible benefit of the most disadvantaged.

It is noticeable Rawls's commitment [30] in defending fundamental freedoms and rights, and equal opportunities for those with similar talents and a similar disposition to conquer and practice them. In addition, it is worth underlining the principle of difference, or *maximin* criterion of social justice, according to which socioeconomic inequalities are only morally acceptable if they aim to maximize the resources available to the most disadvantaged.

The major problem in Rawls's work is the attempt to reconcile the desire for social justice with the preservation of liberal democratic principles and, therefore, the capitalist market system. In his perspective, equity would result from the negotiation or compensation capable of meeting the consensual interests of society. However, one must think about the inequities exhaustively produced by the capitalist notion of equality, which, in the name of individual freedoms, attributes success or failure exclusively to the individuals' competence.

For Rawls, the first problem of justice when facing inequities is to determine principles to regulate social, natural, and historical inequalities, adjusting their profound and long-lasting effects, because when left to themselves, they would threaten the necessary freedom of a well-ordered society. In summary, for the author, the rules of the institutions that serve as a basis for social ordering – due to the principles inherent in a perspective of justice as equity – would be sufficient to guarantee collaboration and solidarity [29,30].

His assumption seems quite questionable when considering concrete societies and their persistent levels of injustice. This is what Siqueira-Batista and Schramm highlight when proposing that equality in Rawls is a difficult task to resolve*, since it determines, a priori and inflexibly, what should be the reason for egalitarianism – in this case, primary goods, thus considered according to the liberal perspective* [31].

Rawls's theory of justice [30] seems devoid of social implications. Formalism prevents the author from approaching reality, making his proposal at least insufficient. By dictating norms and rules a priori, Rawls ends up disregarding society's structural and subjective transformations that support equal rights and, concerning health, universal access to quality healthcare.

The prospect of regulating inequalities and adjusting their effects shows Rawls's unwillingness [30] for structural changes in the social order. According to the author, each individual owns the inviolability founded on justice, to which not even society's common good can overcome. In an eminently fair society, the rights guaranteed by justice would in no way be object of political negotiation, let alone enter in the calculation of social interests.

Rawls's assumption [30] highlights the particular nature of justice and the relative impact of public policies on individuals, corroborating criticisms of the reductionism of social determination of health and the evidence of epidemiology from political, social, and economic analysis. Hence, it is worth mentioning a document published by the Latin American Association of Social Medicine [32] and the statement by Navarro [33], which points to a report by the World Health Organization as a decontextualized accusation of inequalities characterized as injustices, without due critical analysis of social and economic processes.

The relations between inequality, inequity and social determination cannot be reduced to circular analyses of cause and consequence, and under no circumstances complex problems should be examined in isolation or as a consequence of vulnerabilities or risk factors alone [33]. Indifference to the complexity of contexts and its protagonists' perception prevents actions aimed at effective changes, while disqualifying individuals by perceiving them as incapable of reacting to arbitrary realities.

Given the impossibility of easy answers concerning the human being and doing, we must insist on the questions: justice as equality or justice as equity? Is social justice possible in an increasingly unequal and unjust world?

In *Development as freedom*, Amartya Sen [34] shows great discomfort with social inequalities and inequities. Like Rawls, the author emphasizes the importance of eliminating all deprivations of liberty that limit choices and opportunities to exercise citizenship. But while Rawls states that the distribution should be as equal as possible, Sen argues that this policy is insufficient, unable to express the effective deficit of freedom for disadvantaged individuals.

In one of the chapters of *Inequality reexamined*, the Indian author poses a very provocative question: *equality of what*? [35]. He seeks

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to draw attention to the risk that such a concept represents an abstraction unrelated to people's plurality of behaviors and needs around the world.

According to Sen [36], to think of equality in complex terms, one must consider differences without losing sight of social well-being. Thus, the economist proposes equal opportunities, based on the characterization and delimitation of capacities, which refer to a person's effective freedom to make choices based on different guiding operations. In short, these capacities reside in the individual's freedom to choose, among the possible paths, the one that best meets their own needs. The capacities outlined by Sen would measure the individuals' well-being.

Sen [34,36] and Rawls [29,30], each in their own terms, significantly expand the debate on equality and justice by transcending the consumerist perspective imposed by capitalism. Well-being goes beyond *having*; it depends on the subject's capacity of *being* and *doing*. To Sen, the individual is the protagonist of his own existence, able to empower himself when facing challenges that arise during his trajectory, recognizing the obstacles that must be overcome to, from there, choose according to his priorities.

For the economist, it is contradictory and inhumane that people, due to the impossibility of free choice, adjust their desires to the scarcity of opportunities in reality [34]. But how to estimate an individual's well-being? The author himself answers: from the sum of satisfaction versus frustration of desires and preferences, which are our real source of value. Evidently, in a context of inequities, this equation is problematic, since interpreting what is possible in a given situation influences the intensity of the desire and even what each one wants.

In Brazil, to address these issues, Paulo Fortes [37-40] deserves mention. He deals with the concept of justice applied to health – especially SUS – and the concept of equity in Rawls. According to Fortes [37], it is difficult to apply these principles in societies of late capitalism, since people tend to be exclusively concerned with fulfilling individual desires and interests, failing to consider collective needs.

For Fortes [37], the notion of health equity currently considers the difference between people in their concrete realities, i.e., in specific social and health conditions. For the author, an action guided by this idea of equity could guarantee each person the satisfaction of their needs and enable the development of their capacities.

Fortes poses an interesting question*: what would be the ethical criteria guiding a good and fair prioritization of resources related to health care*? [41]. The issue is complex, considering the pluralism of values in the contemporary world, which brings different and varied conceptions about what would be good and just actions. In this context, bioethics could play an important role, seeking *consensus on practical norms that concern the life and health of the human species, building the coexistence of life in society* [42].

For Fortes and Zoboli [43], bioethics must have an autonomous and humanistic perspective, considering the human being in its totality. Its objective, according to the authors, is to humanize health measures and services to guarantee citizens' rights and human dignity, considered according to Kant's categorical imperative [44], whereby each individual must be treated as an end in itself, and never as a means to satisfy others' interests.

Resorting to Kant's formal ethics [45] may function as an argumentative resource, but it is insufficient when facing the complexity of what is real: desires reflect commitments to reality, which may be harder on some individuals than on others. In fact, it is quite difficult for those living on the margins of society, those excluded from globalization [46], who experience multiple deprivations such as the lack of access to education, transportation, basic sanitation, security, employment, and others – rights considered essential for a dignified life [47].

Studies show, for example, how the Brazilian black population is more exposed to vulnerabilities and violence [48-50], or how gender issues determine the reality of women, including indigenous people, throughout the country [51-53]. Thus, assessing the individual advantage of people subjected to rights deprivation and profound inequities, considering only their desires and preferences, contributes to perpetuate the injustice of which they are victims [46].

Sen [34,36] states that each individual must resort to "counterfactual" choices or preferences. But the question remains: would a person choose to live and make certain choices if they were not subject to certain arbitrary circumstances? What if we

extend this question to children and young people, people in development?

The 2018 United Nations Children's Fund Report [54] shows the precariousness surrounding youth, revealing that six out of ten Brazilian children and adolescents live in poverty. These people, subjected to various deprivations, are condemned to remain in precariousness, since they lack guaranteed social rights that would change their circumstances, such as education, health, security, housing, and others.

Given this, in Sen's perspective [34,36], what really matters are not goods and resources itself, but the states and activities to which these goods and resources give access. Valuable operations allows people to be properly nourished and dressed, literate and free of curable diseases, and appear in public without feeling ashamed of themselves. This develops a sense of self-respect, which enables active life in the community. In Sen's words, most people live in deprivation of liberty, as economic poverty denies them the most elementary rights, preventing them from *satiating hunger, obtaining satisfactory nutrition or remedies for treatable diseases, the opportunity to dressing or living properly, and having access to treated water* [55].

Unlike Rawls [29,30], trapped in his liberal theories – and therefore hindered from seeing reality as it presents itself, with all its inequalities and inequities –, Sen [34,36] seems better aligned with those who lack freedom, unprotected and socially vulnerable.

Similarly to Sen [34,36], the bioethics of protection proposes moral thinking attentive to inequalities, adopting as an ethical assumption protect the most vulnerable, fragile, or "incapable". The objective is to implement an agenda based on the idea that an egalitarian and equivalent society necessarily requires unrestricted support for those who need assistance to develop their human potential [56].

The task of the bioethics of protection is to support individuals and communities unable to carry out their life projects, allowing them to achieve dignity as advocated by universal human rights [56,57]. According to Schramm, helping those without the means to survive with dignity *is essential to concretely respect the principle of justice, since applying the value of equity as a means to achieve equality is a sine qua non condition for the implementation of the principle of justice itself* [58].

Inequality and inequity *versus* equity: impacts on health

Despite formal democracy, with laws and decrees, Brazil still has significant levels of social inequality [59], showing that the legal guarantee of rights is insufficient. In this context, citizens are unable to realize their right to health, education, fair wages, etc., as the rules, even if safeguarded by the Constitution, remain as aspirations and promises. For rights to become real, people must empower themselves, be outraged by inequities.

According to the 2018 report of the United Nations Development Program [59], Brazil's Human Development Index has remained stagnant at the 79th position out of 188 countries. Regarding inequality, Brazil is among the nations that lost the most positions, in a condition similar to that of South Korea and Panama. Based on reports like this, it is possible to conclude that the deadliest disease in Brazil is poverty, as the lack of financial resources leads to exclusion, to the lack of access to fundamental goods for development, such as education, freedom, well-being, happiness, health, employment and security.

Poverty interferes with the quality of life and consequently in people's health, understood not only as medical-hospital care, but in a broader sense, as dignity and well-being [34]. Thus, despite its great potential, Brazil cannot overcome the hunger and misery affecting a significant portion of its population [32,33]. To tackle this problem, equity would be more advantageous than equality, by considering that people are different and therefore have distinct needs. Unlike homogenizing equality, equitable action responds to the Marxist principle of *from each according to his abilities, to each according to his needs* [60] or, according to Sen [34,36], each according to his capabilities and functioning.

Equity is understood here as a way to guarantee people – especially the most vulnerable – opportunities to fully develop, according to their own life projects. The fundamental point is to ensure a reasonable health system for all, since the better the services considered essential, the greater the chance of the most needy overcoming

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extreme poverty and deprivation [54], which limit their capacities and potential [32-34,61].

Similarly to Sen [34,36], Siqueira-Batista and Schramm [4] see inequality and exclusion as conditions that go beyond a question of income. Poverty, for example, is seen by the authors as deprivation of necessary goods, such as freedom, well-being, health, rights, employment, and security – in short, as a loss of quality of life. As such, poverty and inequality feed into each other, widening the social gap between rich and poor and reinforcing, in health, the exclusion of the less favored.

In times of globalization [46,62], the abandonment of the excluded is total. The iniquitous reality to which they are subjected increases the risk of diseases that, once contracted, can aggravate their already precarious living conditions. Poverty generates inequality, and inequality reinforces and maintains poverty, in an extremely harmful process, which causes exclusion, marginalization and misery.

The deprivation of health services is partly due to the lack of resources, either material or human, and in precarious situations one must choose who will benefit. In a survey conducted in 2002, Paulo Fortes [63] found that among the interviewees there was tendency for benefiting the "disadvantaged" or "unfortunate," disfavoring situations that could be more cost-effective for society as a whole. However, for the author, choices should be *guided by respect for human dignity and non-discrimination of people due to race, gender, age, or socioeconomic condition* [64].

Given the inequities present in the lives of so many Brazilians, what to do? How to proceed? As discussed, for Sen [34,36,61], in any person's life some things are intrinsically valuable: being protected from preventable diseases, preventing premature death, being well fed, being able to act as a member of the community, acting freely and escaping social determinations – to have opportunities to develop potentialities and capabilities.

For Sen [34,36,61], any discussion on social justice must consider the binomial health-illness. In *People first*, Sen and Kliksberg [65] reiterate the importance of understanding health in its broader sense of life quality, in line with issues such as income distribution, considering human life in the full exercise of its freedom.

In this context, bioethics is responsible for promoting permanent reflections and proposing alternatives and strategies, provoking in each person the desire to recover their functionality [34,36,61] and the capacity to be indignant in the face of the neglect that currently defines the health system [3]. This wager on individual reaction, however, must not neglect pressing the State [65,66] demanding that it plays its role in combating social issues. After all, unjust and avoidable inequalities cannot be naturalized.

Final considerations

Enacted 15 years ago, UDBHR [2] expanded the concepts of bioethics. From this document, internationally recognized, it was possible for the field to transcend the biomedical and biotechnological limits of principlism and foster the debate on social issues that had been neglected until then. Inspired by the UDBHR, this text dealt with equality, justice and equity without forgetting that these concepts were and are thought of in a specific historical time, to meet specific needs and realities, and thus they are polysemic, which makes their exhaustion impossible. From discussing these concepts and their relationship with bioethics, one can think about the concrete social problems that harm the popular classes, decreasing the capacities and potential of the most vulnerable by affecting their well-being and quality of life.

Ethics and health policies are fundamental for achieving well-being in a more supportive world, although there remains a long way to go. An egalitarian and just society will not be spontaneously established: a notion of equity must be highlighted, since it may function as an instrument in the struggle to assert the right to health and, consequently, the right to a dignified and quality life for all. Thus, it is essential to recognize difference, inherent in the idea of equity.

Defending an equitable health system is only the first step in transforming the reality of injustice that plagues Brazil and the world. For equity to stop being merely a principle and become a reality, all citizens must participate, democratically exercising their citizenship, sharing decisions and shaping public health policies.

It is urgent to examine the human practices mentioned here, the factors that determine them and their intentions in specific social interactions. The prospect is that this text interests the reader in reorganizing social spaces, their structures and relationships, since inequalities, misery, poverty and exclusion will only be overcome if each agent contributes to creating equitable public policies, whose absence tends to worsen the social problems addressed here.

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