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UPDATE

Bioethical perspectives on decision-making in times of pandemic

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Abstract

This article aims to identify the contribution of bioethics to resolve decision-making conflicts in healthcare in times of pandemic. The research was based on the authors' personal reflections in a dialogue with the literature and different bioethical perspectives. Historical accounts show that when a society is experiencing an epidemic it starts to function in a mode of social exceptionality, reinforcing the need for a more appropriate form of reasoning before the ethical conflicts that may arise from this situation. Some approaches to bioethics – principlism, personalism, utilitarianism and social bioethics – are briefly examined in order to obtain the elements for guiding the decision-making process. Finally, we suggest some parameters for health professionals, recognizing the value of all human lives, to save as many lives as possible.

Keywords: Pandemics. Bioethics. Personhood.

Resumo

Perspectivas bioéticas sobre tomada de decisão em tempos de pandemia

Este artigo busca identificar contribuições da bioética para enfrentar conflitos relacionados à tomada de decisão em tempos de pandemia. Trata-se de texto elaborado a partir de reflexões pessoais dos autores em diálogo com a literatura de diferentes perspectivas da bioética. Com fundamento em relatos históricos, argumenta-se que, durante epidemias, a sociedade passa a atuar em modo de excepcionalidade, o que exige argumentação mais apurada para se posicionar ante os conflitos que surgem. Analisam-se então diferentes vertentes teóricas – principialismo, personalismo, utilitarismo e bioética social –, recolhendo de cada uma elementos que podem nortear a tomada de decisão. Com base nessas contribuições, propõem-se parâmetros para a atuação dos profissionais da saúde, reconhecendo igual valor em cada vida humana, com o propósito de salvar o maior número de pessoas possível. Por fim, aponta-se para a responsabilidade de agentes políticos.

Palavras-chave: Pandemias. Bioética. Pessoalidade.

Resumen

Perspectivas bioéticas sobre la toma de decisiones en tiempos de pandemia

Este artículo tiene como objetivo identificar la contribución de la bioética para hacer frente a los conflictos relacionados con la toma de decisiones en tiempos de pandemia. Se trata de un texto elaborado con base en las reflexiones personales de los autores en diálogo con la literatura de diferentes perspectivas de la bioética. Con base en los relatos históricos, se argumenta que, durante epidemias, la sociedad pasa a actuar en modo de excepcionalidad, lo que requiere una argumentación más precisa para posicionarse ante los conflictos que surgen. Se analizan entonces diferentes vertientes teóricas – el principialismo, el personalismo, el utilitarismo y la bioética social –, recogiendo de cada una los elementos que pueden orientar la toma de decisiones. Con base en dichas contribuciones, se proponen parámetros para la actuación de los profesionales de la salud, reconociendo el mismo valor en cada vida humana, con el propósito de salvar al mayor número posible de personas. Por fin, se apunta hacia la responsabilidad de los agentes políticos.

Palabras clave: Pandemias. Bioética. Personeidad.

The authors declare no conflict of interest.

In times of pandemic, healthcare professionals are required to make complex decisions, such as choosing which patients will receive a potentially life-saving treatment while aware that those who do not might be practically being left to die. Before this distressing situation, theoretical and technical frameworks are important for establishing decision-making criteria. Such considerations need a rigorous analysis of arguments, as well as frankness and honesty, in order to avoid interminable discussions leading to no concrete outcomes. This article analyzes whether current approaches in the field of bioethics are effective within this context.

This study aims to answer the following question: which bioethics approach provides the best ethical arguments to face the conflicts arising from the pandemic? Answering this involves addressing several other questions, such as: is it reasonable to privilege young patients over older ones, considering that morbidity and mortality are higher among the elderly? Is it prudent to disregard this group even though the legislation has specific laws for them? Do health professionals commit an ethical infraction and a crime when they do not provide emergency aid to vulnerable people? The search for answers to such questions is not limited to the field of bioethics, but this article intends to follow some clues, while recognizing the need for further studies.

In mid-December 2019, several cases of a respiratory disease of unknown origin were identified in China. The symptoms were dry cough, fever, fatigue and, less frequently, gastrointestinal symptoms. Initially, the disease affected 66% of the fish sellers in a market in Wuhan, the capital of Hubei Province ¹. On the 31st of that month, the World Health Organization (WHO) was officially informed about this outbreak of pneumonia cases of unknown cause concentrated in the region, and in the next day the market was closed by the Chinese authorities.

The etiological agent was later identified as a new betacoronavirus, initially named 2019-nCoV and then renamed Sars-CoV-2, the cause of the disease whose official name became "Covid-19". With the spread of the disease to other countries, the WHO declared a public health emergency of international concern on January 30, 2020, but only on March 11 the Covid-19 outbreak was officially declared a pandemic, with millions of reported cases and hundreds of thousands of deaths².

The purpose here is, through personal reflections, establish a dialogue with authors from several areas, based on theoretical frameworks. This is a study conducted under the impact of the

pandemic, bearing in mind that no easy consensus is expected on this matter.

Societies in times of pandemic

In describing the Plague of Athens in 430 BC, Thucydides ³ stressed the fact that the epidemic occurred in a context of social and moral disorganization. From this statement, we could understand that the cause of the plague would be moral degradation or that society was under exceptional circumstances because its immorality was exacerbated by the disease ³.

A first aspect of this exceptional situation is the inefficiency of regular treatments. In this sense, Thucydides' report of the Plague of Athens echoes every time society experiences a new epidemic: neither were the physicians at first of any service, ignorant as they were of the proper way to treat it, but they died themselves the most thickly, as they visited the sick most often; nor did any human art succeed any better⁴. It is as if Thucydides was narrating the Covid-19 pandemic by pointing out that health professionals (as we would call them today) were affected themselves the most thickly, as they visited the sick most often⁴.

The most dramatic image of Thucydides is that of the unburied bodies throughout Athens, contrary to all ancient Greek standards of normality, given the sacred obligation to properly bury the dead. Similarly, Galen – the Greek physician who was in Rome and witnessed the outbreak of the First Antonine Plague (AD 165-170), describing it, according to Gozalbes Cravioto and García García, as a serious illness, often deadly and which simultaneously affected a large number of people⁵ – recommended that funerals should not be held within the city limits, as was the custom at the time.

In these distressing periods, relationships between people change, to the astonishment of Boccaccio, who experienced the Black Death outbreak (1348-1350): but even worse, and almost incredible, was the fact that fathers and mothers refused to nurse and assist their own children, as though they did not belong to them⁶. Another dramatic passage is found in the works of Muratori, who witnessed the early 18th century's plague in Spain: the women who are breastfeeding must have their children taken immediately from them after the illness begins to show, and puppies must then be found to suck their milk when needed⁷.

Among the more recent fictional reports, there are two fictional books that describe the unfolding of dramas similar to the current pandemic. In 1947,

Albert Camus published *The Plague*⁸, in which he considered the absurdity of human existence, pondering on the simultaneity of evil and solidarity evidenced in the fight against an epidemic that tests the moral boundaries of the residents of Oran, a city in Algeria. *Blindness*⁹, a novel by the Portuguese writer José Saramago, describes the "white blindness" that spreads uncontrolled among the population of a city in an unspecified part of the planet. It is a parable about moral blindness in times of a disease of unknown cause, in everything similar to the current pandemic, in the midst of which, despite significant scientific advances, we remain "blind". Our hope is that the current "plague" will be transitory, as that described by Saramago.

These excerpts only intend to point out how recurrent are many situations experienced in the current pandemic. Shocking scenes are being witnessed, such as the unbelievable images of mass-grave burials or trucks lined up to collect corpses to be buried in haste, without due ceremony. There is a recurrent astonishment that cannot be ignored in the epidemics, when norms and rules prove to be ineffective and everyone is subjected to exceptional conditions.

The initial point of this article is that, in the midst of a pandemic, society starts to function in a mode of exceptionality, and political measures and social behaviors that would be unacceptable in other contexts are now openly defended. In healthcare, it is as if emergency situations, previously uncommon and concentrated in certain services, suddenly became the norm.

Drawn from past epidemic experiences, this point needs to be highlighted, as we cannot be afraid to take emergency measures when they are required, just as they should be avoided when the situation changes. This is a position typical of bioethics, understood as a field of knowledge aimed at providing practical guidelines for contextualized action. This position echoes many traditional approaches that understand moral action as action in context.

The next topic to be addressed is how the main bioethical approaches may contribute to decision-making in times of moral conflicts. The main perspectives addressed here will be principlism, personalism, utilitarianism and social bioethics. However, before proceeding it is necessary to provide a brief notion of conflicts in this field of knowledge.

Because it values diversity – interdisciplinarity, interculturality and moral diversity –, bioethics does

not seek to provide definite answers for problems concerning human action. This field of knowledge analyzes situations of conflict for which reasonable and prudent courses of action can be established after an open and diversified debate. Therefore, self-proclaimed carriers of the truth place themselves outside the field of bioethics, which is open to those who argue that the truth can be reached, or at least glimpsed, as a result of a collective search. When derived from consensus, actions do not generate conflicts. The problems arise when there are disagreements about the course to be followed, or when the suggested course of action offends the values and convictions of those involved.

The major principles of bioethics

Those who begin to study bioethics soon encounter the four widely known precepts – beneficence, non-maleficence, autonomy and justice – proposed by Beauchamp and Childress ¹⁰ in 1979 in *Principles of Biomedical Ethics*, which would become the main reference of the "principlist" approach to bioethics. This perspective aimed to draw from religious and philosophical traditions universal precepts to be applied in the resolution of ethical conflicts arising from biomedical practice.

The principles presented by Beauchamp and Childress ¹⁰ have historical basis. Beneficence, for example, is a hallmark of the medical ethics introduced by Hippocrates in Ancient Greece. The emergence of bioethics started a debate on ethical dilemmas in health, helping to identify problems and to seek solutions. However, principlism – an approach that was developed in the United States and became dominant – later came to be criticized for its pragmatism and supposedly universal conclusions.

Within the context of pandemics and "social exceptionality," the application of the four-principle approach depends even more on the virtues and ability to discern of those involved. This dependence "loosens" these precepts, as they cannot be applied blindly or disregarding the context. Therefore, they cannot be considered from a closed, restricted perspective. Autonomy, for example, should be given priority, as long as this does not cause harm to other people.

Autonomy is limited by the principle of justice, as when people are forced to home confinement or social isolation, restricting the right to come and go. This conflict is also present in experimental interventions involving human beings aimed at developing instruments to bring normality back. Informed consent, the ultimate expression of

autonomy, can even be dispensed in such cases, where the potential social relevance of a study is greater than the damage to individual rights.

When health services are overwhelmed, healthcare professionals often have to decide who will be deprived of the best treatment available. The urgency to decide leads to anguish, and one must act in many cases without being able to consider the circumstances more deeply. To lessen this burden, it is common to establish official protocols — which is a mistake, since "ethical algorithms" cannot prevent conflicts and, sometimes, lead to impertinent or even unjust interventions.

The ethics of conducting an in-depth assessment of a situation and balancing beneficence with potential damage and respect for autonomy with justice is essential in emergencies. In the end, decision-making should always be based on this careful assessment. Complex circumstances do not allow for a superficial evaluation, and in these moments technical knowledge must be used to help discernment. Thus, principlist bioethics will be present in any decision-making concerning health, even though it proves to be insufficient in many cases.

All with equal dignity: how to choose?

Another relevant approach to bioethics is personalism ¹¹, which is based on Christian principles and is linked to specific aspects of human health and scientific research. Because of its religious foundation, personalism is not always well received. However, this approach agrees with the worldview of most health professionals who were raised in a society with a strong Christian heritage. In view of this, personalist bioethics provides a very reasonable perspective for addressing the moral conflict analyzed here.

The reflections arising from this religious tradition reveal a high view of the human being. The term "person" has several connotations in bioethics, but in personalism its meaning is indisputable: each individual – throughout life, from the embryo to old age – for being called to existence as image and likeness of God, is considered a person, and this condition is neither enriched nor impoverished by social and historical events.

This understanding of the human being entails the affirmation and defense of individual dignity, which is not a matter of achievement nor can be qualified. Thus, one's life cannot be disregarded, relativized or depreciated by another person or by society. However, according to the personalist

approach, life may be donated, offered or sacrificed by the individual whenever the situation demands in the defense of values as noble as life itself or even higher. The intransigent and obstinate attachment to the transience of life on Earth is not justified, since this life has its basis in eternity. These are the assumptions of personalism concerning healthcare matters.

Personalist bioethics does not understand the affirmation of dignity as a defense of individualism, but rather emphasizes the social and relational dimensions of the person in a consistent defense of the dignity of the other. A personal commitment to society is thus established, which can lead to voluntary sacrifices to welcome and assist those most in need.

According to personalism, patients can legitimately renounce care that would only mean a painful prolongation of their own existence. If the individual cannot exercise autonomy, others — such as family members or health professionals — may also limit care provision, as long as the procedures being waived are ineffective in the situation, and would only prolong the agony. Decisions like this are supported by several approaches in bioethics.

However, this issue is limited in relation to decision-making in times of pandemic, since many therapies being offered – use of respirators, for example – are not ineffective, and there are real chances of curing the disease. How to choose then which patient should be treated? There are occasional reports of one patient consciously renouncing treatment in favor of another. This is a noble gesture, supported by personalist bioethics. But, apart from these rare cases of altruism, what to do?

This question can only tell health professionals that the life of all human beings has equal dignity and value, so that as many people as possible should be saved. But when the concrete situation does not make it possible to save everyone, this approach can only mourn the losses, without treating them as an ethical problem or responsibility of those involved. In this perspective, moral responsibility only applies when one can act freely and consciously.

The limits of personalist bioethics may be illustrated with an example: a daycare center catches fire and someone enters the building to save the children. However, this person saves only those who are closest to the door and can be reached more easily. A personalist approach would accept the following reasoning: this person's option was to try to save everyone, and that was done as best as possible. However, personalism would not find acceptable if the same actions were performed with

the aim of saving only those lives that the rescuer considered most valuable.

Utilitarianism: the greatest good for the greatest number

Utilitarianism is an ethical theory developed at the end of the 18th century by the English philosopher Jeremy Bentham ¹². It takes a consequentialist approach to ethics that stands in opposition to principlist or deontological ethics, arguing that decisions should be validated or refused based on an evaluation of their consequences, and not on *a priori* motivations, values or duties. In general, a proper course of action, according to a utilitarian approach, should result from a calculation to maximize happiness and minimize unhappiness, so that the former is always greater than the latter.

One of the major criticisms of utilitarianism concerns the definition of "happiness," that is, the good that should be maximized. Bentham 12, following a hedonistic interpretation, initially suggested that happiness would be the bodily "pleasure" that one experiences, while "pain" would indicate the evil to be minimized. Bentham even proposed quantitative indicators to measure pleasure in terms of intensity, duration, certainty, propinguity, fecundity and purity. His disciple, John Stuart Mill 13, defined happiness in qualitative terms, establishing subjectively qualified criteria that go beyond a mere assessment of physical sensations – the pursuit of love and beauty, physical and emotional tranquility, intellectual pleasure, of cultivating good relationships and friendships, etc.

Since then, utilitarianism has been adopted and further developed by several authors. In bioethics, especially over the last decades, this approach has been increasingly gaining ground. For example, utilitarianism is being applied to discussions about animal rights: when it is argued that pleasure and pain (or the interests) of all sentient beings must be considered in utilitarian assessments, as well as in ethical discussions on public healthcare, particularly concerning the allocation of limited resources ¹⁴. In these cases, the utilitarian perspective proposes that priority should be given to the resources most capable of promoting the health of the greatest number of people for the longest possible time.

Fortes ¹⁴ points out ordinary examples of the application of utilitarian calculations in public health, such as mass vaccination at the expense of exclusively curative approaches, as the latter are less

efficient and more costly. However, utilitarianism meets resistance even in the field of bioethics. For example, the focus on efficiency is under criticism because it implies decisions based on delivering the greatest benefit at the lowest cost, subjecting healthcare to economic calculations focused on reducing expenses of public or private systems ¹⁵.

Concerning clinical guidelines in exceptional situations, such as the use of mechanical ventilation devices in intensive care units during the Covid-19 pandemic, the utilitarian approach has been the standard response in many countries. This approach provides the rationale for prioritizing young people and adults to the detriment of older people. According to utilitarian calculations, the elderly would have less time to live, and therefore less chance to enjoy pleasure, health or happiness ¹⁶. However, these guidelines are very criticized for entailing unacceptable forms of age discrimination and an inadmissible violation of human dignity and basic rights.

Social bioethics: priority to vulnerable groups

"Social bioethics" is understood here as the approach developed in Latin America since the 1990s, when Latin American bioethicists began to identify the limitations of theories produced in developed countries, which would not properly respond to local ethical conflicts. These limitations were related to the inability of American and European bioethics to go beyond purely clinical and hospital contexts, as they almost always focused on patient autonomy and beneficence from the perspective of health professionals. Until then, issues related to socioeconomic vulnerability were disregarded, such as lack of access to healthcare, social exclusion, hunger and violence, among others that still have a direct impact on the lives and health of most of the population of Latin America and Caribbean.

Authors such as Márcio Fabri dos Anjos ¹⁷, Volnei Garrafa ¹⁸ and Fermin Roland Schramm ¹⁹ started to address the social dimension in their reflections on bioethics. Over the years, this approach has been further developed by other authors, from other parts of the world and fields of knowledge. Despite occasional differences, which are expected in an interdisciplinary field still under development, what characterizes Latin American social bioethics is a politicized, critical and contextualized approach to ethical conflicts involving health, taking into account its individual, collective and global dimensions.

The main contribution of social bioethics in the context of the Covid-19 pandemic is the prioritization of socially vulnerable groups. Social bioethics argues that health services should favor the most excluded, marginalized and vulnerable individuals. This position can be supported, for example, on the basis of the seminal ideas of Anjos ¹⁷, who in the late 1980s introduced the notion of "mysthanasia" in the field of bioethics. This concept aimed to demonstrate how end-of-life decisions unfairly affect the most poor, who often suffer an early death due to lack of access to hospitals or basic health conditions, such as sanitation and food.

Schramm's work ²⁰, in turn, calls attention to processes of health vulnerability, that is, to unfair mechanisms that negatively affect groups that are not able to defend their own interests. This situation led Schramm to develop the "bioethics of protection," an approach that gives priority to public actions and policies aimed at protecting the most vulnerable.

Along the same lines, Garrafa and Porto ²¹ propose an "intervention bioethics," which emphasizes the responsibility of the State and civil society for the serious social problems that generate inequalities. The authors developed a particular utilitarian approach — called "equity-oriented utilitarianism" — to be applied in contexts such as those of Brazil and Latin America, where there is an excluded and vulnerable majority that should be given priority in public policies.

Recently, in a dialogue with social bioethics, Cunha ²² laid the foundations for a "critical bioethics" based on the so-called "negative ethical universalism," which aims to identify a concrete universal value to support norms and actions ²³. This value is the suffering (common to all peoples and places on the planet) resulting from economic and environmental exploitation related to globalization, which unfairly affects the most vulnerable groups. Shortly after, in 2018, Sanches, Mannes and Cunha ²⁴ developed the concept of "moral vulnerability," calling attention to the processes that legitimize exclusion, stigmatization and discrimination through the imposition of a hegemonic morality, often supported by scientific, economic, sociological or theological theories.

According to the Latin-American social bioethics approach, decision-making parameters, both in treatments and in protocols, norms and public policies, must prioritize groups there are socially and economically vulnerable, historically excluded, unprotected and exploited. Prioritizing these groups in the midst of the most severe health crisis in recent times would not only redress

unacceptable historical injustices, but also provide a didactic presentation of a new post-pandemic social organization, fairer and more ethical.

Covid-19 in Brazil: ethical parameters

Besides conforming to the law of the country, any ethical decision-making in health matters must also be in accordance with the human rights principles established in international agreements and must be reached in the light of bioethics. Both the Universal Declaration of Human Rights 25 and the Universal Declaration on Bioethics and Human Rights 26 consider unacceptable all forms of discrimination. Similarly, the Code of Medical Ethics in force in Brazil states among its fundamental principles that medicine is a profession that must serve the health of human beings and the population and must be practiced without discrimination of any nature 27. Brazil's legal system also includes the Statute of the Elderly, which in its article 15 ensures the provision of comprehensive healthcare services to the elderly (...) for the purposes of prevention, promotion, protection and recovery of health, including special assistance for diseases that preferentially affect the elderly 28.

In the next section, we present some contributions of bioethics for addressing the conflicts arising from the pandemic, which are a result of the examination of theoretical references and approaches performed in this study. Before that, however, we must highlight that bioethics considers it unlikely to find consensual solutions to recurring moral conflicts in healthcare. Therefore, the aim should be seeking the most reasonable and prudent solutions.

A proper bioethical approach should consider scientific facts (the territory of evidence-based medicine) and the moral values of all those leading the decision-making process (the territory of human subjectivity). With these constraints, it is clear that protocols and consensuses established by associations of specialists should serve only as guiding principles, never as the sole guidance to clinical deliberations. This is a crucial assumption, because health professionals, especially doctors, tend to base their decisions only on scientific evidence, emphasized during their formation. Also essential is to consider each clinical case as a unique event that has its own specific nosological and biographical variables ²⁹.

After these reflections, we present some decision-making parameters for this context of Covid-19 pandemic:

- Decision-making should never be based on theories that assign different values to the life and dignity of different people. There are no criteria for establishing that one human being is worth more or less than another. Choosing may be necessary, but restricting the decision to age is to diminish the complexity of the situation and assume an ideological position at the expense of ethical reflection.
- 2. Always bear in mind the principle of beneficence and the need for respecting the patients' autonomy.
- 3. Affirm, every day, the purpose of taking good care of everyone. In cases where proper care is crucial for survival, rely on the principle of justice, which implies saving as many people as possible.
- 4. When the dramatic daily events of a pandemic force choices to be made, decision-making, based on technical criteria, should aim to save the largest number of patients. Reductionist solutions based on a single criterion must be avoided.
- Always submit norms and their context to a critical assessment, seeking to support public policies that guarantee the right to health and strengthen health systems, so as to prevent this exceptional situation from repeating itself with the same degree of severity.
- 6. Understand the limitations of personal responsibility. When structural conditions of healthcare make it impossible to save someone, the loss of a patient cannot be seen as a deliberate act of the professional who provides care.

Final considerations

The theme of this study does not allow for definitive conclusions, given the complexity of the decision-making process. However, the conflicts arising in times of pandemic can be addressed by different approaches to bioethics. The openness to interdisciplinary dialogue, aimed at the mutual enrichment between the arguments of different bioethical approaches, suggests the need for other types of reasoning that do not support the simplistic

proposition that it is necessary to choose between the lives of a younger or older patient.

The ethical parameters proposed here should not be understood as a ready-made and final guidance for health professionals, because, ethically, the responsibility is always of those who act, and not of the guidelines. Moreover, it is the role of bioethics to provide recommendations relevant to the context in question. It is thus necessary to highlight two types of agent: the political agents, which can implement policies and standards that affect the health system; and the individuals - health professionals - who need to make decisions in specific and restricted institutional and structural contexts. This categorization can be discussed, as political action certainly involves subjective decisions, while the actions of individuals are also political, but distinguishing between these two spheres helps to determine responsibilities.

When political agents act, they do not have to face the patients affected by their decisions. Their actions might cause deaths or preserve lives, but the consequences of their choices are usually neither direct, nor always evident. Health professionals, on the other hand, suffer directly from the effects of their actions, as the impact on the patient is immediate. In this sense, the social bioethics approach can establish parameters for holding political agents accountable when they do not act on the basis of the best scientific or technical evidence available, when they establish rules to protect certain particular social groups or when they implement measures that exclude the most vulnerable populations from health services.

The importance of political agents is so evident that the Covid-19 pandemic has had a very uneven impact on different countries and on different even regions within the same country. A quick analysis of the pandemic's impact on different places is enough to reveal the consequences of their decisions. Their responsibility is manifest, and it is even possible to statistically assess the impact of a given policy on the number of deaths. Bioethics' relevance stands out in this context due to its potential to denounce decision makers for obviously discriminatory and unfair policies and norms. Political agents are thus expected to be held responsible for harmful measures implemented on the basis of exclusionary and elitist assumptions.

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