The bioethical principle of autonomy in caring for the health of Indigenous peoples

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Abstract
This article seeks to characterize the respect to the principle of autonomy in the care to indigenous peoples in the Brazilian territory, based on reports on experiences and a bibliographic review. It concluded that this principle must be specially consolidated in the practical actions of health care developed alongside peoples of different cultures, as is the case of indigenous communities.


Resumo
Princípio bioético da autonomia na atenção à saúde indígena
Neste artigo busca-se caracterizar o respeito ao princípio da autonomia no atendimento a populações indígenas em território brasileiro, tendo por base relatos de experiência e uma revisão bibliográfica. Concluiu-se que esse princípio deve ser especialmente consolidado nas ações práticas de cuidado à saúde desenvolvidas com as populações de culturas diferenciadas, como é o caso das comunidades indígenas.


Resumen
Principio bioético de la autonomía en la atención a la salud indígena
Este artículo busca caracterizar el respeto en el principio de autonomía en la atención a las poblaciones indígenas en territorio brasileño a partir de informes de experiencia y revisión de la literatura. Se concluyó que este principio debe consolidarse especialmente en las acciones prácticas de asistencia sanitaria dirigidas a las poblaciones de diferentes culturas, como las comunidades indígenas.

Indigenous health, for those outside this population, is an issue which permeates the history of the American continent. Multiple actions have given rise over time to a complex set of social attitudes regarding the health of traditional Amerindian populations, such as those formulated and executed by religious missions or the armed forces, always integrated with public policies conducted mostly by government agencies. Assistance, teaching, and research institutions develop projects which are often disconnected from the aspects which are essential for the adequate performance of their mission.

Thus, concepts such as life, cosmology, and ontogenesis and diverse conceptions of the health-disease process should be at the core of these actions, projecting the basic bioethical principle of autonomy more than ever in a diffuse, collective, and communitarian space, instead of restricting it only to individuals. Thus, from a brief literature review and the experience of healthcare providers caring for Indigenous populations, this study intended to characterize the respect for the autonomy of Indigenous patients inserted in their own culture, in such a way that the focus on diagnosis and therapy, reduced to its component based solely on the biomedical model, should be relativized.

Currently, Indigenous health care in Brazil is linked to the Unified Health System (SUS), structured by the Indigenous Health Care Subsystem (SasiSUS), created in 1999 thanks to Indigenous participation in the health reform. From then on, policies became decentralized and began to be coordinated by the Indigenous Special Health Districts (DSEI), organized in centers distributed across strategic cities. Providing those involved with social control is one of the characteristics of the model, whose pillar is the training and integration of Indigenous health agents. Moreover, it was established that the biomedical model centered on the disease would be ideal, and that culture and collective values should be highlighted.

Method

This is a descriptive and qualitative study, with experience reports and literature review conducted using the PubMED and SciELO databases, from 2008 to 2018. Using a Boolean operator “and,” and ignoring year of publication, the descriptors chosen were: “bioethics,” “Indigenous populations,” and “autonomy.”

Results and discussion

Understanding Principism: the principle of autonomy and its importance in healthcare

Proposal for professional ethics codes vary according to each country but most are based on the same principles: autonomy, beneficence, non-maleficence, and justice. Such principles derive from the publishing of the Belmont Report in 1978, a joint effort to unify practices of medical ethics in research and treatment of human beings, after a series of abuses were verified. Among these principles, autonomy is the most controversial since it engenders frequent debates on polemical topics such as the requirement of informed consent, euthanasia, and advance directives.

Considered by many the main pillar of bioethics, autonomy can be defined as patients’ inherent right to actively decide on the diagnostic and therapeutic procedures to which they will eventually be subjected. Although this theme has raised progressive interest in the medical literature, patients’ decisions were rarely considered the most important aspect of treatment planning.

It is a relevant component of modern medical ethics and has been raising awareness in academia and society. However, such discussion has is yet to result in practical changes due to the influence of well-established and often intransigent cultural and government values.

Autonomous individuals are capable of making decisions regarding their own lives, based on their concepts, criteria, and freedom. Thus, they can take responsibility for their choices. More broadly, autonomy is individuals’ ability to govern themselves, disposing of rules set by others and adopting attitudes and performing actions according to their own intentions. Therefore, a certain level of individual freedom and a guarantee of this right constitute necessary features for the exercise of autonomy.

As long as subjects are capable of discerning among options and making their own choices,
they should be encouraged to participate in the complex processes constituting their treatments. For this to happen, it is necessary that physicians offer patients subsidies for their decisions, in a clear and noncoercive way. This combination of disclosed information and opportunity to decide shapes the participatory model of treatment, considered by many as ethically ideal.4

Thus, physicians cease to be the “key which opens doors” to become technical advisors, guiding patients on the various options available to them and their possible consequences and encouraging them to make decisions. One barrier to consolidating this new form of doctor-patient relationship is the traditional sense of power which is attributed to physicians. In the logical and automatic exercise of their activities, they often underestimate patients’ cognitive capacities by believing them unable to analyze facts and alternatives.

This participatory model goes against the paternalistic model of care, in force in most of the world and mostly managed by governments themselves. The organizational base of this model is still centered on issues such as maintaining control over individuals and communities’ decision-making power. This characterizes public paternalism, in which states grant themselves the right to decide and direct the choices they consider optimal.5

Public paternalism is clearly opposed to the autonomous formation of preferences, a form of “domination” as it restricts individual autonomy. By regulating what it considers the most appropriate types of choices and minimizing people’s participation, this model stifles individual choices. Moreover, in some cases, states avoid deliberating by themselves, favoring the creation of preferences they find satisfactory and thus more subtly and slowly interfering in decisions. Therefore, based on their preferences, they decide what would be best for the collectivities, imposing their choices as part of communities’ routine and creating a favorable community opinion which increasingly solidifies asymmetry processes.

Principlism in Indigenous peoples’ health care relationships: “colonialist ethics”

Dominance over choices and preferences, in addition to the coercion of autonomy—central elements of the paternalistic care model—give massive rise to issues related to the implemented public health policies. However, this ignores a previous understanding of individuals or groups’ cultural components. This problem becomes even more evident in Indigenous peoples’ health since the asymmetry in decision-making power is notorious regarding the offered strategies, as there is a clear conflict regarding Indigenous autonomy, as the alleged protection of minority cultures produces certain isolation against external influences, reducing these peoples’ options.

Principlism has an Anglo-American origin and was initially based on Belmont principles—respect for persons, beneficence, and justice. Later, after philosophers Beauchamp and Childress’ studies, it evolved into the four foundations which are currently recognized: justice, respect for autonomy, beneficence, and non-maleficence. These principles always aim at the well-being and preservation of individuals.6

However, such principles alone are probably unable to guarantee the bioethical integrity of Indigenous peoples and of ethnic and tribal minorities spread over the continents. This is because many of these peoples replace individualism with community identity: Indigenous and tribal peoples have peculiar ways of seeing, living, and relating to the world. Many preserve traditions, beliefs, and customs based on an ancient wisdom which other cultures have difficulty understanding, a situation in which community identity overcomes individual ones.

In truth, Amerindian thought has always been undervalued by cultures considered dominant, cultures which minimize or ignore the former’s agricultural, food, religious, and healthcare practices. A true “colonialist ethic” has been built, assuming that dominated peoples are cognitively inferior and incapable of deciding on their lives, future, and problems, decisions left to the dominator.

Europeans, for example, began invading Indigenous lands in the 16th century and imposed that it would be “better” for Indigenous peoples to work in fields, wars, manual labor, and mining. Moreover, they forced them to be evangelized, clearly underestimating their capacity for self-support, religious beliefs, and cultures. From then on, these peoples’ autonomy has been constantly curtailed, with the justification of their supposed
In its own definition, the principle of autonomy is based on individuals’ capacity for choice, considering that everyone has their own concept of life, disease, death, beliefs, and culture, elements which influence their choices. The opposition to the principle of autonomy regarding dealings with Indigenous peoples is not restricted to the past. On the contrary, the colonialist format is still used today, even after 500 years of the discovery of Brazil, devaluing the fact that the option for any way of life is legitimate as long as it is the result of individuals’ free choice.

One such example is the Rapanui community, of Polynesian origin, which inhabits the Easter Island, Chilean territory in the Pacific Ocean: in 2003, an American university, authorized by the Chilean institutions, collected material for DNA analysis and macular degeneration testing, supposedly with the intention of offering them lenses. However, they used a consent form in Spanish, which is inaccessible to that people. These facts show that Indigenous peoples are among vulnerable groups, that is, those who are discriminated because of a characteristic they did not choose, but which was attributed to them, causing stigmatization. In this example, a “civilized” people used scientific and economic power to call themselves superiors, self-attributing a value derived from cultural evolutionism theories.

Stating that a group is socially vulnerable is to admit the incompetence of the state of preventing the perpetuation of these subjects or communities’ fragility, helplessness, and lack of protection.

Indigenous health practices in Brazil: respect for the principle of autonomy

There are approximately 820 Indigenous peoples scattered throughout Latin American countries. They speak 653 languages and total almost 45 million people, representing 8% of the population of the American continent. Brazil, according to the Brazilian Institute of Geography and Statistics, hosts about 305 Indigenous peoples dispersed throughout its territory, with several degrees of contact or isolation with non-Indigenous populations. Many of them already inhabit the outskirts of large cities, whereas others still find themselves geographically isolated in remote locations in the Amazon.

For decades, the Brazilian government has shown interest in offering more adequate health conditions to Indigenous peoples. At the same time, there are constant transformations in the way this situation is handled, in view of the progressive changes in these populations’ epidemiological profiles. Moreover, the various Indigenous nations show cultural diversity, each of which stands differently regarding certain issues, such as urbanization, peri-urbanization, and the loss of or aggression against their cultural identities.

Since 1999, with the creation of the Indigenous Special Health Districts (DSEI), the organization of the planning of health actions to be offered to these peoples has improved in all Brazilian states. It also had a positive impact on the preservation of sanitary conditions, but always with the challenge of facing difficulties inherent to each region and, at the same time, mitigating the process of attrition of the original cultures of each nation or ethnic group.

If Indigenous communities have historically suffered primarily from infectious and contagious diseases which were the main responsible agents for their reduction and suffering, they now face more and more chronic, degenerative, and metabolic diseases, such as diabetes, hypertension, and cardiovascular disease, which resulted from changes to their eating habits and sedentarism. An increase in the number of their members suffering from alcoholism and mental disorders has also been observed, which previously were non-existent. All of this has increased the challenge of providing equitable care to population, according to the principles governing the SUS.

Certainly, the paternalistic care model predominates since the same health measures offered to the Brazilian people in general were imposed to Indigenous peoples: endemic disease control, breastfeeding incentive, child growth and development, hypertension, and diabetes control programs.

It has been speculated that this model would be more adequate and superior but there are no studies proving that such methods and programs are really feasible and ideal for these populations. The literature has even less knowledge on whether the traditional way these peoples use to take care of some of such problems would not be as or more effective than the academic model.
based on scientific knowledge and theories. For example, we lack studies proving whether exclusive breastfeeding up to six months is superior to the diet some Indigenous peoples offered their infants. The Kakraibá in Minas Gerais and the Wari in Rondônia, for example, expose half their children to teas before they reach two months of age, whereas the Yamanaua, in Acre, offer them even beverages based on milk formulas, banana, and manioc.

We must also reflect on the fact that, for many Indigenous peoples, the processes of health, disease, and death have different meanings than for non-Indigenous peoples.

**Experience reports on the treatment of Indigenous people: the challenge of interculturality**

Still under construction, the concept of interculturality represents an advance in relation to multiculturalism in its broadest sense, that is, the coexistence of distinct cultures in the same place and society without conflicting relations among them. The complexity of this idea suggests that a healthy and fruitful interaction among several cultures can be beneficial, complementary, inclusive, and articulated.

Respect for Indigenous cultures has been a challenge for Indigenous health teams because approaching and offering them services can mean a real aggression to the Indigenous collectivity. However, some experiences with peoples with whom contact has recently been established show that less invasive attitudes, centered on the individual and considering the ethical particularities and traditions of each people can be more fruitful.

Thus, it is believed possible to develop care practices based on scientific evidence but guided by multicultural bioethics, requiring a broad view free of prejudice, in which anthropology and health practices should be in accordance with the needs of the community and not only respond to the interests of an inflexible health system.

**The bioethical focus regarding autonomy**

One of the authors of this text has more than 17 years of experience in providing care to Indigenous patients in the interior of state of Amazonas suffering from epilepsy and other chronic neurological diseases. He observed that some individuals have difficulty to understand the biomedical concept of disease and the need for continued, often indefinite, treatment.

“Sometimes we see children almost every day suffering from countless seizures, without that provoking any apparent sense of despair or discomfort in their parents, unlike what we see in our daily practice of neurology” (HM).

This phenomenon is based on beliefs in the culture of Indigenous peoples inhabiting various countries in the American continent. Several authors have studied this fact and found that various ethnic groups attribute convulsive and epileptic phenomena to imbalances between the human and animal spirits within each individual.

In Central America, for example, descendants of the Maya civilization believe that different animals inhabit people of higher (puma or hawk) and lower social castes (sheep or deer). Thus, it makes no sense for them to take medication to solve an imbalance among elements whose nature belongs to popular cultural identity.

Argentine, Paraguayan, and Bolivian Indigenous peoples also believe that epilepsy is a conflict between the “human” and the “animal” soul, triggered by the influence of an enemy who would have cast some kind of spell over the individual. Pajés would then have to solve this conflict by counteracting the power of the enemy’s spell, which is done in front of the whole village using hallucinogenic plants. The Guarani, on the other hand, think that this unbalance between the spirits of epileptic individuals should be treated by associating known roots and leaves which have been used for centuries in the form of infusions, teas, and rituals.

In Peru, it was common to treat epilepsy with condor blood, cougar hearts, or testicles from other animals, usually rubbed on specific stones which would release spiritual energies to be infused into the patient. The Aztecs believe that epileptic syndromes are the result of possession by dangerous deities, a form of punishment for sins, causing head contortions and movement of arms and legs, as reported in 16th century manuscripts. Since that time, those affected were recommended to isolate themselves in a temazcalli, a wooden construction with a dome and walls in which they were subjected to baths and
infusions of various plants, such as artichoke, ambrosia, coffeeweed, magnolia, etc\textsuperscript{20}.

Brazilian Indigenous peoples have a variety of interpretations as to the origin of epilepsy, and the perspective of the Kamayurá, from the Xingu region, is well known. They believe that the illness is due to the revenge of the spirit of the armadillo killed by the hunter’s bow and arrow. The treatment for the “armadillo disease” would then be administered with typical plants of the region, tsimó and wewurú\textsuperscript{21}.

Studies show that some peoples have already acquired the ability to associate their traditional methods and treatments with Western medicine. This was clear in a study conducted in Potiguara villages on the coast of Paraíba: 66% of the Indigenous people interviewed said that modern medicines are already part of the village routine, and 30% reported that they use both synthetic drugs and the medicinal plants and treatments recommended by their ancestors\textsuperscript{22}. The process and rituals surrounding the illness and death of older adults in Indigenous societies in which the transmission of knowledge occurs in ways other than writing also constitute a situation in which bioethical principles need to be highlighted. As an example, we offer the following episode from another author of this article:

“In one of the Indigenous communities that I visited as a physician; I was treating an older man who lived in a community about a day’s boat ride away from a hospital center. The patient was considered to be one of the last pajés of the group and he was very ill. He had been taken on previous occasions to a mission, army hospital but treatments had had no effect. Many members of the community asked for him not to be removed from the community again as it was important that his last conversations with community authorities and older people in the vicinity of the village could be held, as there was important knowledge to be passed on or clarified. In a brief (translated) conversation with the patient, he asked to remain in his village. There was great fear in the community, as in many cases older patients were taken out of the village against their will and never returned. So, I stayed in the region for about seven days, until the old pajé died. I witnessed the expressions of sadness in various communities since the unanimous feeling (at least that was how saw it) was that a large part of the knowledge of these people had irreversibly disappeared. An important piece of a culture was fading away, rather than only an old man’s existence having ended” (NPO).

Final considerations

Given the great complexity regarding interculturality, a more reflective view on the theme of this article is proposed. For this, it is necessary that the persons involved get rid of historically dominant thoughts about health.

Several bioethical questions may arise from this reflection:

1. Is the right to apply the technicist view of illness and treatment justified? Would acting this way significantly incentivize the loss of Indigenous cultural identity and tradition? Considering the reality of Indigenous peoples’ health and their indisputable right to autonomy over their own lives, how can we assist them in a culturally sensitive way, with a dialogic position or proposal which is not mere imposition?

2. Are we or are we not infringing the principle of autonomy if we prescribe medicine without understanding Indigenous individuals and communities’ point of view about an illness?

3. In health care practices, is the dissemination of knowledge valued to make Indigenous people more enlightened and empowered about the disease process or is it simply seeking to impose a biomedical and reductionist point of view?

Faced with this polemic, almost two decades ago, Lolas\textsuperscript{23} commented that Latin American countries had cultural and institutional characteristics which made it necessary to reorganize and adapt bioethics, aiming at an approach which would give more value to Indigenous peoples’ religious, communal, and ancestral traditional medicine practices. Such practices should be accepted as therapeutically complementary, including their rituals and the use of plants that are typical to them, in addition to integrating such elements into the practices of Western medicine. It becomes necessary to ask: “Whose autonomy should be protected, the individual’s, the community’s, or both?”
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Thus, the creation of a "Latin American bioethics" is suggested, a proposal in which Indigenous issues and state institutions be organized in a systematic work to engender more adequate legal and administrative contexts to the current challenges. Moreover, this proposal aims to plan, regulate, and guarantee the rights of the peoples, protecting their genetic and cultural heritage and including their health practices.

When the plan for public health care policies for Indigenous peoples was created, there was a small advance in this inclusion, making mandatory the presence of Indigenous health agents in the multiprofessional teams serving these communities. This would be a first link, although still weak, to unite the traditionally paternalistic, dominating health system and the assisted population, trying to give them some voice in collective and individual health issues.

As proposed by the regulation of the program and suggested by Santos and Pereira, professionals, especially physicians, should seek to integrate their practices with the support of shamans and value knowledge resulting from millenary cultures, respecting them and promoting greater effectiveness in their health practices.

These themes and reports configure situations in which the bioethical principle of individual autonomy joins the principle of collective cultural autonomy. Moreover, they reinforce the need of health care to culturally diverse populations to consider not only the biomedical and epidemiological context but also the cross-cultural horizon so that health actions neither promote ethnic traumas nor be collectively teratogenic. The reviewed studies addressing aspects of Indigenous culture highlight the cultural differences of these peoples about life and death, health and illness, and being in the world. From the bioethical point of view, these differences need to be considered in health actions since the principle of autonomy must guide other studies to be conducted.

Based on our literature review and the problems exposed in the individual experiences reported, we conclude that the principle of autonomy must always be considered and expanded in all relationships with Indigenous populations, especially in planning and executing health actions. This will only be possible if attitudes and proposals are culturally sensitive and adapted to be efficient in improving the living and health conditions of Indigenous peoples.

Furthermore, it is up to the Brazilian state to ensure public policies which guarantee the exercise of interculturality in the elaboration and execution of health policies aimed at Indigenous peoples. To achieve this goal, they must be involved, consulted, and listened to when these policies are created, that is, they must actively participate in social control.

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Participation of the authors
Marcos Manoel Honorato and Norimar Pinto de Oliveira reviewed the literature, wrote the theoretical framework, and described their personal experiences related to the subject. Robson José de Souza Domingues and José Antonio Cordero da Silva provided theoretical support and analyzed the written content. Fernando Morgadinho Santos Coelho and Renata Maria de Carvalho Cremaschi conducted the final revision of the text and contributed with the translation of the abstracts and adaptation to the journal.

Received: 4.14.2020
Revised: 11.23.2021
Approved: 2.18.2022