

Bioethical considerations on the doctor-indigenous patient relationship

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Abstract

The principle of autonomy was a significant bioethical achievement in terms of its positive impact on the physician-patient relationship. The search for balance in the paternalistic doctor and indigenous patient relationship is fundamental for the symmetrical maintenance of such relations. In this context, it is essential that the medical professional considers and accepts the existence of social and cultural diversity when planning therapeutic strategies that aim to ensure the autonomy of the patient, the family and community, thus guaranteeing a good quality of service and of life. The aim of this article is to characterize, from the perspective of bioethics, the challenge faced by the physician-indigenous patient relationship, indicate critical situations and suggest means for an ideally harmonious relationship between these cultures in the area of health.

Keywords: Indigenous population. Health of indigenous peoples. Physician-patient relations. Bioethics.

Resumo

Considerações bioéticas sobre a relação médico-paciente indígena

O princípio da autonomia foi conquista bioética significativa, uma vez que teve impactos positivos na relação médico-paciente. A busca do equilíbrio no contato entre o tradicional paternalismo médico e a especificidade cultural do paciente indígena é fundamental para a manutenção simétrica dessa relação. Diante disso, é indispensável que o médico considere e admita a existência da diversidade social e cultural para elaborar projetos terapêuticos que visem a autonomia do paciente, da família e comunidade, garantindo, assim, bom atendimento e qualidade de vida. Este artigo objetiva caracterizar, sob o enfoque da bioética, o desafio enfrentado na relação médico-paciente indígena, pontuar situações críticas e sugerir aos profissionais estratégias para estabelecer relações idealmente harmoniosas entre essas culturas na área da saúde.

Palavras-chave: População indígena. Saúde de populações indígenas. Relações médico-paciente. Bioética.

Resumen

Consideraciones bioéticas sobre la relación médico-paciente indígena

El principio de la autonomía fue una conquista bioética significativa, en la medida en que tuvo impacto positivo en la relación médico-paciente. La búsqueda del equilibrio en el contacto entre el tradicional paternalismo médico y la especificidad cultural del paciente indígena es fundamental para el mantenimiento simétrico de esta relación. Frente a ello, es indispensable que el médico considere y admita la existencia de la diversidad social y cultural para elaborar proyectos terapéuticos que contemplen la autonomía del paciente, de la familia y de la comunidad, garantizando así una buena atención y calidad de vida. El presente artículo tiene como objetivo caracterizar, desde el enfoque de la bioética, el desafío enfrentado en la relación médico-paciente indígena, puntuar situaciones críticas y sugerir a los profesionales estrategias para establecer relaciones idealmente armoniosas entre esas culturas en el área de la salud.

Palabras-clave: Población indígena. Salud de poblaciones indígenas. Relaciones médico-paciente. Bioética.

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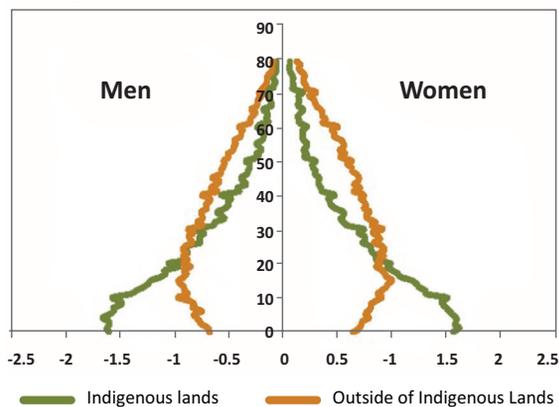
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Declararam não haver conflito de interesse.

From the time of the arrival of the first Portuguese to Brazil to the 1970s, the Brazilian indigenous population in decreased drastically in size and many peoples were extinct. This decrease came to be regarded as a historical contingency, something regrettable, and in the last decades of the 20th century, this situation began to change. Since 1991, the Brazilian Geography and Statistics Institute (“Instituto Brasileiro de Geografia e Estatística” - IBGE) included indigenous people in the national demographic census and the number of Brazilians who considered themselves indigenous grew 150% on the 1990s decade, a growth rate almost six times greater than that of the general population. There was a yearly increase of 10.8% in the population and a total average of 1,6% of growth.

Today, according to data from the last IBGE census conducted in 2010, the Brazilian population totals 190,755,799 people. According to the census, 817,963 of these are indigenous, of which 502,783 or 61.5% live in indigenous areas and 315,180 or 38.5% live in urban areas, thus showing that they are present in all states, including the Federal District. Regarding the sex and age composition of the study population, Chart 1 shows the prevalence of both sexes in indigenous lands until at least the beginning of adulthood, and the broad base indicates a high birth rate among women¹.

Chart 1. Composition of the indigenous population by sex and age, with residence declared as inside or outside indigenous lands, according to the 2010 Demographic Census²



The predominance of women and children in indigenous lands indirectly implies the real need for differentiated public health policies, with effective medical care focused primarily on the needs of this population, which is vulnerable due to its genotype and ethnic minority status. Considering the historical situations of injustice and inequality faced by indigenous people in Brazil, starting with their late

recognition as part of the Brazilian population and the aggression to the rights of their personality, this article aims to determine the ideal conditions of health care for these people from a new angle, based on the bioethical reference of autonomy in the physician-patient relationship, taking into account the rich, conflicting and diverse culture of the indigenous population.

Goal

To identify and analyze possible challenges faced by clinical bioethics in intercultural and/or interethnic contexts. The study object are the relationships established between physicians and patients from indigenous communities contemplated by the implementation of the National Policy on Health Care for Indigenous Peoples (“Política Nacional de Atenção à Saúde dos Povos Indígenas” - PNASI), equalizing the patient-physician autonomy in search of an ideal relationship.

Methods

For this study, a bibliographical review and comparative analysis of the articles found was performed between the 1st and 30th of July 2016 to delimit the theme, also considering the policies and directives of health for indigenous peoples in the Brazilian Unified Health System (“Sistema Único de Saúde” - SUS). The research strategy involved searching for articles that had, in their titles, the terms “bioética” (“bioethics”), “cultura indígena” (“indigenous culture”), “autonomia médico-paciente” (“pysician-patient autonomy”) and “saúde indígena” (“indigenous health”) associated to the boolean operator “and”, so as to get the most adequate studies to the theme.

In total, 169 articles were found, double entries excluded. Regarding the inclusion criteria, the research included works in English, Portuguese or Spanish and was not restricted to the date of publication, preference for more current studies occurred only in cases of the same line of study and/or very similar discussions on the topic addressed. The exclusion criteria were limited to studies published in languages other than those chosen and to those who did not approach bioethics in relation to the topic explored, resulting in a base of 45 articles to study the theme, to plan and elaborate the final text.

The National Policy on Health Care for Indigenous Peoples (“Política Nacional de Atenção à Saúde dos Povos Indígenas” - PNASI)

Since the Federal Constitution of 1988, the Brazilian State began to acknowledge the rights and specificities of indigenous populations in Brazil, as well as the need to incorporate them into the SUS and to develop public policies that favored them. In order to expand medical assistance to these populations, the Indigenous Health Care Subsystem (“Subsistema de Atenção à Saúde Indígena” - SASI) and the Special Indigenous Sanitary Districts (“Distritos Sanitários Especiais Indígenas” - DSEI) were created in 1999³.

Through partnerships among public institutions and indigenous and other civil society organizations, DSEIs aimed to promote the health of these populations at the medical and dental levels. The Ministry of Health (“Ministério da Saúde” - MS) was responsible for elaborating norms and guidelines to be implemented by the National Health Foundation (“Fundação Nacional de Saúde” - FUNASA), as set forth, respectively, in articles 2 and 3 of Decree 3,156/1999, ratified in September of the same year by Law 9.836 (Lei Arouca), which attributed this responsibility to SASI under the SUS⁴.

In 2002, the MS and FUNASA launched the PNASI⁵ under the justification of adopting a different model of care to guarantee these peoples a better exercise of their citizenship regarding health promotion, protection and recovery. The PNASI, in turn, determines that the multidisciplinary health teams in the districts should include indigenous health agents, nursing technicians, nurses, dentists and physicians, similar to the Family Health Program. It also provides for the systematic participation of anthropologists and other professionals and technicians who are specialists in indigenous issues in each DSEI, in order to create a well-defined dynamic, geographical, population and administrative ethnocultural space, and therefore promote among these populations full coverage, access and acceptability before the SUS^{5,6}.

The view of the medical professional

It must be considered that the university training of managers, health professionals and, above all, the medical professional is generally constructed according to the scientific determinism of epidemiology and biomedicine. These disciplines generally do not include solid anthropology content of health, administered almost always in graduate programs.

This situation contrasts with what prescribes the axis of ethical-humanistic training recommended by the Ministry of Education. Moreover, this deficient training is indicated in the literature as incapable of responding to the various intercultural conflicts faced by doctors today, which are related to the ignorance of the differentiated cultural matrix that supports the indigenous medical systems and justifies their practices.

Therefore, the conception that the “civilized” (medical professional) must evolve the “primitive” (indigenous patient) and that scientific knowledge, reduced to the interactions between pathogens and hosts, regulation and deregulation genetics and other mismatches of organic functions, should clarify or validate local knowledge, evidencing its supremacy is still frequent in health actions. This ethnocentrism in the local planning of health actions is responsible for decontextualizing behaviors, simplifying demands and, above all, for generalizing the needs of individuals and their communities⁷.

As for the actual practices of care, it is common for the physician to see the diagnostic or therapeutic activities of traditional indigenous systems as elements to be tolerated or, at most, incorporated in an accessory way, but not articulated with their scientific knowledge. There is a tendency to classify them as resources of symbolic efficacy or, at most, complementary or alternative, and their practitioners are simply ignored or disqualified as partners capable of intervening in intercurrent diseases or injuries.

The view of the indigenous patient

In the view of most indigenous peoples, the health-disease process goes beyond the rigid notions of disease and treatment currently posited by the medical sciences, more specifically by medicine, which, in turn, is based strictly on pathophysiological processes of the human organism. The indigenous conception of sickness and healing is part of a cosmological order and involves invisible forces of nature; the meaning of the disease is far beyond our limited perspective of the physical body. This process involves not only physical suffering but also spiritual and moral suffering.

Even though there is no consensus, since, according to a survey by the Socio-Environmental Institute (Instituto Socioambiental)⁸, in Brazil there are now approximately 250 indigenous peoples listed in the 2010 Census. There is a clear divergence regarding the understanding of the illness between them and the medical professional. As mentioned, this understanding does not correspond to the pathologically structured

process defined by medicine and postulated throughout the scientific milieu, even for peoples who coexist since the dawn of colonization with the unbridled urbanization and industrialization of the geographical spaces of their sacred territories^{9,10}.

Among the adversities faced by the indigenous patient when subjected to paternalistic medical treatment is the difficulty of adapting to the new routine of idleness in which patients are hospitalized, away from their relatives and their community during treatment, and living with people with often extremely divergent culture and values¹⁰. The indigenous patient expects the physician to be in contact with multiple territories of knowledge, welcoming the diversity and socio-cultural plurality that each individual can contain, and then establishing therapeutic projects that grant autonomy to the patient, family and community, thus ensuring good care and quality of life¹¹⁻¹³.

Usually the sick Indian first consults with the “pajé” (shaman), who indicates and implements therapies he deems appropriate, such as herbal treatment, plant baths, or smoke. He also determines if the disease is “of material cause” or “of spiritual cause,” considered a consequence of the non-observance of the code of behavior, causing profound imbalance in the human spirit. In the first case, the patient is treated by health professionals and the shaman at the same time. In the second case, if it is found that it is a disease of an indigenous or spiritual nature, and once one believes in the duality of the soul, the characteristic ritual of a shaman (“pajé”), derogatively and erroneously termed “pajelança”, is performed. Usually it presents good results, bringing vivacity back to the patient, as it corresponds to a treatment¹⁴.

The ideal physician-indigenous patient relationship

The physician-patient relationship should be a continuous process and involve four main components: consciousness, knowledge, ability and cultural encounter. In other words, the union of practical and scientific knowledge and respect for the patient’s culture and autonomy¹¹. It is essential that the medical professional be willing to listen to the indigenous patients and understand how they perceive their experience of illness, in an attempt to build a differentiated attention together aiming at the best treatment⁹.

It is expected that the health care service will count on a multiprofessional team and that it will open space for the dialogue between patient

and team, mainly strengthening the bonds of trust between the physicians and the indigenous patients. For a successful quality care, good training of the professionals is necessary, which must go beyond the mere physician-patient relationship, contemplating the sociocultural context and the different conceptions about health, illness, treatment and the individual himself. This way, means are sought to bring cultures together and contribute mutually to the decision on the treatment, valuing and respecting the patient’s autonomy in order to guarantee integral, resolute and responsible care¹⁵.

The physician is expected to develop strategies to clarify the diagnosis and procedures to be performed, as well as to adjust the environment and the hospital diet whenever possible, respecting the patient’s beliefs. Whenever possible and opportune, the physician should approach the community to learn the local language and get to know their life habits, the territory and the peculiarities of the indigenous people, thus broadening their understanding of the health-disease process. In this way, the link between physician and patient is established, and there is more respect and trust in the care provided.

The physician should also integrate the support of the shaman and other members of the community with training in the health area, or that of translators who facilitate communication and mutual understanding, whenever necessary, thus conveying greater security to the patient and giving greater effectiveness to the service. Likewise, the support and involvement of medical staff in campaigns and work in communities, bringing information about care, prevention, immunization and fighting diseases, are important to strengthen ties between doctors and patients, as well as improving the quality of life in the villages¹³.

Bioethics in the physician-indigenous patient relationship

*Bioethics is the systematic study of the moral dimensions – including moral vision, decisions, conduct, and policies – of the life sciences and health care, employing a variety of ethical methodologies in an interdisciplinary setting*¹⁶ focused on the solution of concrete conflicts in diverse contexts and consequences resulting from the encounter between different cultures. Cultural diversity should not be neglected; however, their practices can not be an excuse to justify the violation of human dignity, as

required by Article 12 of the *Universal Declaration on Bioethics and Human Rights*:

*The importance of cultural diversity and pluralism should be given due regard. However, such considerations are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms, nor upon the principles set out in this Declaration, nor to limit their scope*¹⁷.

The attempt to unify the sociocultural values of the different populations of Brazil is a task doomed to fail, since it would put an end to the best of all peoples, their cultural inheritance, that is, the ways of expressing unique feelings and values. However, from the normative point of view, it is possible to share human rights-based behaviors - such as condemning genocide, murder, torture, rape, slavery, enforced disappearances, child and elder abuse and racism - in search of more organized, conducive and harmonious in society.

When they feel harmed, many indigenous communities resort to rights protection mechanisms to hold the State accountable for violations. It is clear that indigenous peoples perceive human rights as allied instruments and are able to assert their values and ideals, such as the right to land and cultural identity, for example. However, human rights do not always adequately respond to the sociocultural peculiarities of different peoples, given their generalist stance. From this perspective, it is possible to understand the difficulty in reconciling distinct interests, keeping the cultural identity untouched, without adaptations.

However, not every bioethical conflict presupposes a violation of human rights, as the example cited by Lorenzo¹⁸ of the child of the Tukano ethnic group, from an indigenous group living on the banks of the Uaupés River, in the territories of the Brazilian Amazon, Colombia and Venezuela. The child was bitten by a jararaca snake and hospitalized in a health unit of Manaus, where the father requested the entrance of the shaman for the child to be treated according to the practices of their culture, but had his request denied. Faced with the negative, the father sought legal measures to remove the child from the health unit and to receive traditional treatment, exercising their right to autonomy.

Aware of the situation, the director of a local hospital suggested that the father should continue to be admitted to the ICU because of the seriousness of the case, subject to both Western medicine and traditional Tukano medicine given by the shaman.

The proposal was accepted by the father, happily culminating in the cure of the child.

There was certainly a bioethical conflict of cultural basis regarding the treatment. However, the physician who acted as director of the hospital had the sensitivity of allowing the patient and their caregivers to experience fundamental aspects of their culture, using their own medicine long with the Western medicine. In this way, a consensus was reached and none of the parties involved violated human rights; both worked to restore the patient's health.

Interventional measures that do not respect culture should be avoided; the intercultural approach presumes the perception of the culture, the object of analysis, without an ethnocentric look, eliminating negative or prejudiced stereotypes, to create a relationship of empathy. Thus, cultural exchange strategies are always adequate for any conflicts in which there is a tenuous or explicit violation of human rights.

Distinctly, in other types of conflicts, as in the case of the "indigenous infanticide" tradition, there is a clear violation of the human rights of children and women, although the context is different. In these situations, in most cases of indigenous villagers, even anthropologists begin to admit that it may be better to apply the principle of the aforementioned Article 12¹⁷, according to which cultural diversity and pluralism should not be used to justify the violation of any human right. In this example, when traditional practices reflect the inferior position of women and children in a given patriarchal society, dialogue and intercultural mediation are not enough.

The solution of cultural-based moral conflicts, whatever their nature, is based on the principle that there should be no hierarchy of cultures, and the protection of the vulnerable, irrespective of the cultural community to which they belong, is an inexorable duty of the State¹⁹. However, normative instruments that do not represent the human diversity end up perpetuating social conflicts. Conflicts generated by cultural differences should be discussed symmetrically and pluralistically, subsidized by bioethics, since the defense of these specificities of indigenous health has brought relevant improvements to this population²⁰. Recently, the birth of twins of the Araweté people was in the news. The children were rejected by the indigenous community. According to the belief of this community, this means something catastrophic. In this case, the National Indian Foundation ("Fundação Nacional do Índio" - FUNAI) embraced the children and sent them for adoption, an alternative commonly employed for this type of conflict.

In the processes of “intercultural relationship” and social mobility, some indigenous people have acted as health agents in certain areas, especially in the southern region of the country. This activity has greatly facilitated the physician-patient relationship, since medical performance is allowed without disrespecting the beliefs and habits of the people cared for. The indigenous health workers know the limits of each of the parties and seek to reconcile the different ways of health care, which results in beneficial integration and stimulates the autonomy of the relationship^{21,22}. It is very important that the health services seek to get closer to the population cared for to understand their customs and adapt the forms of care prescribed by Western medicine to their cultural and religious needs.

It is in this sense that we speak of the process of intermediality or therapeutic plurality as a way of adding knowledge based on traditional medicine and other forms of non-medical knowledge in theory and practice, as is the case of the intrinsic knowledge of indigenous health²³. Consideration should also be given to drug interactions when attempting to reconcile indigenous treatment and conventional medical treatment, and the need to understand why this physician-patient relationship is possible. These difficulties were described by Vieira, Oliveira and Neves²³ in the experience reported with the Truká people. Reconciling these forms of treatment is a sign of recognition of plurality and respect for cultural diversity.

For Santos²⁴, the intercultural imperative is difficult to achieve due to competing conceptions of equality and difference, which bring the right to equality when there is inferiority and the right to difference when there is disfigurement. The author also points out that *not all equalities are identical and not all differences are unequal*²⁵.

Final Considerations

As public health policies allocate professionals in regions historically excluded from health care or in contact with people whose conception of health differs from that of the West, ethical conflicts will emerge. As each culture has very particular characteristics, their resolution, therefore, depends on the predisposition to consensus and other theoretical tools for reflection, as well as pragmatic skills for the dialogue not yet very clearly defined in the epistemological scope of clinical bioethics¹¹.

The principle of autonomy was a significant bioethical achievement, since it had a positive impact on the physician-patient relationship, even though the increase in the complexity of this relationship has generated more ethical conflicts. In this way, the balance between autonomy and paternalism is fundamental to maintaining the symmetry of the physician-patient relationship. In the context of health services provided in urban environments and societies with Western characteristics, this relationship lives in the era of “shared decision” and, therefore, the physician and patient are co-responsible for their choices²¹.

The physician should act as a mediator of health promotion, providing indigenous patients with all the necessary means to improve their health, guaranteeing universal access to the network with equity and cultural respect. It must also be made available to mutual learning in the face of the diversity of situations, thus realizing the importance of having a genuine interest in becoming involved with the culture of the other. For this, it must be prone to adapt to local conditions, needs and possibilities, considering the various social, cultural and economic systems. On the other hand, greater openness of the indigenous communities is necessary for them to enjoy the services offered by SUS, which are rightfully theirs.

For an ideal relationship, the physician who attends patients of indigenous origin needs to consult with and study them as a whole, individually and collectively, from a broad approach that considers the environment where he lives and the characteristics of his daily life, way of life and eating habits. Acting this way, the physician acts as an agent that comprehensively interprets and evaluates all the complex scientific, cultural, and environmental factors that surround the unique physician-indigenous patient relationship.

Professionals need to be able to prioritize the various medical problems that affect the patient, establishing the proper sequence so that the treatments meet the correct priorities and the peculiarities of the indigenous person. This provision is indispensable for establishing major diagnostic hypotheses, scheduling complementary examinations, if necessary, and then prescribing the appropriate therapy for each case. When it is considered necessary, they should seek the help of the shaman for more comprehensive treatments, joining forces for a greater good that is expected to have an impact on the patient’s acceptance and

adherence to the treatment due to the trust and the knowledge that is added.

When considering the situation from the point of view of the patient, who is intended to be cared for with medical science, the need arises for an integrative element that reestablishes health, that is, a reliable reference that can guide him during treatment doctor. The indigenous patient needs to understand the interest and commitment of their caregiver, an essential factor in the fight against the disease. Trust is deposited in the physician and, from his/her advice, the new situation is faced: the one of being ill. It is not just another illness, a case study or diagnosis, because it is not just that. The disease always happens in concrete individuals, and because of this, it has individuality, personality, its peculiarities, family, social and especially cultural characteristics. The disease is really personal and nontransferable, as the subject itself, as the soul and the being.

The physician-indigenous patient relationship can be considered a delicate one, since the conflicts generated come from different perceptions of the health-disease process, which are permeated by ethical, moral and cultural divergences of the parties

involved. This relationship requires dialogue and mutual understanding of the different points of view in order to build effective links so that it is possible to balance the doctor's technical-scientific knowledge and the knowledge associated with the spiritual aspects of the indigenous patient. The sole objective is to restore health without this intervention causing harm to the patient, without compromising the autonomy of both or disrespecting the cultural diversity inserted in that context.

It is a delicate exercise of shared intercultural dialogue to establish solid relationships based on the differences peculiar to the Brazilian people. One must start from the basic premise that cultures are incomplete and problematic in themselves as far as their conceptions of human dignity are concerned, thus justifying the need for plurality, for if each culture were as complete as it is thought, there would only be one and truly universal culture²⁴. The effective construction of the physician-indigenous patient link involves the understanding, brought by bioethics, of the plurality of human beings, grouped together or not. Thus, the effective bond built also evolves as an affective bond.

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Participation of the authors

Ana Carolina Giolo dos Santos was responsible for the review of the literature and for contributions to the text. Ana Paula Marconi Iamarino contributed with the survey and selection of the articles cited, considerations on the theme and revision of the manuscript. Jaqueline Boni da Silva chose the theme, elaborated the study design and contributed with the review of the literature, the selection of articles cited and considerations on the theme. Ana Zollner contributed to the discussion on the theme and dynamic corrections to the text. *Clávis Francisco Constantino* contributed in the suggestion of the theme for the study, in the sequential text revisions and the final correction. All authors participated in the revision of the article.



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